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Pranee Liamputtong
Editor

Handbook of Research Methods in Health Social Sciences

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Pranee Liamputtong
Editor

Handbook of Research Methods in Health Social Sciences

With 192 Figures and 81 Tables

 Springer

Editor

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*To my mother:
Yindee Liamputtong
and
To my children:
Zoe Sanipreeya Rice and Emma Inturatana
Rice*

Preface

Research is defined by the Australian Research Council as “the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies, inventions and understandings.” Research is thus the foundation for knowledge. It produces evidence and informs actions that can provide wider benefit to a society. The knowledge that researchers cultivate from a piece of research can be adopted for social and health programs that can improve the health and well-being of the individuals, their communities, and the societies in which they live. As we have witnessed, in all corners of the globe, research has become an endeavor that most of us in the health and social sciences cannot avoid. This Handbook is conceived to provide the foundation to readers who wish to embark on a research project in order to form knowledge that they need. The Handbook comprises four main parts: Traditional Research Methods in Health and Social Sciences, Innovative Research Methods in Health Social Sciences, Doing Cross-Cultural Research in Health Social Sciences, and Sensitive Research Methodology and Approach. This Handbook attests to the diversity and richness of research methods in the health and social sciences. It will benefit many readers, particularly students and researchers who undertake research in health and social science areas. It is also valuable for the training needs of postgraduate students who wish to undertake research in cross-cultural settings, with special groups of people, as it provides essential knowledge not only on the methods of data collection but also salient issues that they need to know if they wish to succeed in their research endeavors.

Traditionally, there are several research approaches and practices that researchers in the health social sciences have adopted. These include qualitative, quantitative, and mixed-methods approaches. Each approach has its own philosophical foundations, and the ways researchers go about to form knowledge can be different. But all approaches do share the same goal: to acquire knowledge that can benefit the world. This Handbook includes many chapters that dedicate to the traditional ways of conducting research. These chapters provide the “traditional ways of knowing” that many readers will need.

As health and social science researchers, we are now living in a moment that needs our imagination and creativity when we carry out our research. Indeed, we are now living “in the new age” where we will see more and more “new experimental

works” being invented by researchers. And in this new age, we have witnessed many innovative and creative forms of research in the health and social sciences. In this Handbook, I also bring together a unique group of health and social science researchers to present their innovative and creative research methods that readers can adopt in their own research. The Handbook introduces many new ways of doing research. It embraces “methodological diversity,” and this methodological diversity will bring “new ways of knowing” in the health and social sciences. Chapters in this Handbook will help to open up our ideas about doing research differently from the orthodox research methods that we have been using or have been taught to do.

Despite the increased demands on cross-cultural research, discussions on “culturally sensitive methodologies” are still largely neglected in the literature on research methods. As a result, researchers who are working in cross-cultural settings often confront many challenges with very little information on how to deal with these difficulties. Performing cross-cultural research is exciting, but it is also full of ethical and methodological challenges. This Handbook includes a number of chapters written by researchers who have undertaken their research in cross-cultural settings. They are valuable to many readers who wish to embark on doing a cross-cultural research in the future.

Globally too, we have witnessed many people become vulnerable to health and social issues. It will be difficult, or even impossible, for health and social science researchers to avoid carrying out research regarding vulnerable and marginalized populations within the “moral discourse” of the postmodern world, as it is likely that these population groups will be confronted with more and more problems in their private and public lives as well as in their health and well-being. Similar to undertaking cross-cultural research, the task of conducting research with the “vulnerable” and/or the “marginalized” presents researchers with unique opportunities and yet dilemmas. The Handbook also includes chapters that discuss research that involves sensitive and vulnerable/marginalized people.

This Handbook cannot be born without the help of others. I would like to express my gratitude to many people who helped to make this book possible. I am grateful to all the contributors who worked very hard to get their chapter done timely and comprehensively. I hope that the process of writing your chapter has been a rewarding endeavor to you as well. My sincere appreciation is given to Mokshika Gaur who believes in the value of the volume on research methods in health social sciences and has given me a contract to edit the Handbook. I also thank Tina Shelton, Vasowati Shome, and Ilaria Walker of Springer who helped to bring this book to life.

I dedicate this book to my mother Yindee Liamputtong, who has been a key person in my life. It was my mother who made it possible for me to continue my education amidst poverty. Without her, I would not have been where I am now. I also dedicate the book to my two daughters, Zoe Sanipreeya Rice and Emma Inturatana Rice, who have formed an important part of my personal and professional lives in Australia.

Sydney, Australia

Pranee Liamputtong

Contents

Volume 1

Section I Traditional Research Methods in Health and Social Sciences	1
1 Traditional Research Methods in Health and Social Sciences: An Introduction	3
Pranee Liangputtong	
2 Qualitative Inquiry	9
Pranee Liangputtong	
3 Quantitative Research	27
Leigh A. Wilson	
4 The Nature of Mixed Methods Research	51
Cara Meixner and John D. Hathcoat	
5 Recruitment of Research Participants	71
Narendar Manohar, Freya MacMillan, Genevieve Z. Steiner, and Amit Arora	
6 Ontology and Epistemology	99
John D. Hathcoat, Cara Meixner, and Mark C. Nicholas	
7 Social Constructionism	117
Viv Burr	
8 Critical Theory: Epistemological Content and Method	133
Anastasia Marinopoulou	
9 Positivism and Realism	151
Priya Khanna	
10 Symbolic Interactionism as a Methodological Framework	169
Michael J. Carter and Andrea Montes Alvarado	

11	Hermeneutics: A Boon for Cross-Disciplinary Research	189
	Suzanne D'Souza	
12	Feminism and Healthcare: Toward a Feminist Pragmatist Model of Healthcare Provision	205
	Claudia Gillberg and Geoffrey Jones	
13	Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology	223
	Patti Shih	
14	Empathy as Research Methodology	237
	Eric Leake	
15	Indigenist and Decolonizing Research Methodology	253
	Elizabeth F. Rix, Shawn Wilson, Norm Sheehan, and Nicole Tujague	
16	Ethnomethodology	269
	Rona Pillay	
17	Community-Based Participatory Action Research	285
	Elena Wilson	
18	Grounded Theory Methodology: Principles and Practices	299
	Linda Liska Belgrave and Kapriskie Seide	
19	Case Study Research	317
	Pota Forrest-Lawrence	
20	Evaluation Research in Public Health	333
	Angela J. Dawson	
21	Methods for Evaluating Online Health Information Systems	355
	Gary L. Kreps and Jordan Alpert	
22	Translational Research: Bridging the Chasm Between New Knowledge and Useful Knowledge	367
	Lynn Kemp	
23	Qualitative Interviewing	391
	Sally Nathan, Christy Newman, and Kari Lancaster	
24	Narrative Research	411
	Kayi Ntinda	
25	The Life History Interview	425
	Erin Jessee	
26	Ethnographic Method	443
	Bonnie Pang	
27	Institutional Ethnography	457
	Michelle LaFrance	

28	Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis	471
	Sarah J. White	
29	Unobtrusive Methods	491
	Raymond M. Lee	
30	Autoethnography	509
	Anne Bunde-Birouste, Fiona Byrne, and Lynn Kemp	
31	Memory Work	527
	Lia Bryant and Katerina Bryant	
32	Traditional Survey and Questionnaire Platforms	541
	Magen Mhaka Mutepefa and Roy Tapera	
33	Epidemiology	559
	Kate A. McBride, Felix Ogbo, and Andrew Page	
34	Single-Case Designs	581
	Breanne Byiers	
35	Longitudinal Study Designs	603
	Stewart J. Anderson	
36	Eliciting Preferences from Choices: Discrete Choice Experiments	623
	Martin Howell and Kirsten Howard	
37	Randomized Controlled Trials	645
	Mike Armour, Carolyn Ee, and Genevieve Z. Steiner	
38	Measurement Issues in Quantitative Research	663
	Dafna Merom and James Rufus John	
39	Integrated Methods in Research	681
	Graciela Tonon	
40	The Use of Mixed Methods in Research	695
	Kate A. McBride, Freya MacMillan, Emma S. George, and Genevieve Z. Steiner	

Volume 2

41	The Delphi Technique	715
	Jane Chalmers and Mike Armour	
42	Consensus Methods: Nominal Group Technique	737
	Karine Manera, Camilla S. Hanson, Talia Gutman, and Allison Tong	

43	Jumping the Methodological Fence: Q Methodology	751
	Tinashe Dune, Zelalem Mengesha, Valentina Buscemi, and Janette Perz	
44	Social Network Research	769
	Janet C. Long and Simon Bishop	
45	Meta-synthesis of Qualitative Research	785
	Angela J. Dawson	
46	Conducting a Systematic Review: A Practical Guide	805
	Freya MacMillan, Kate A. McBride, Emma S. George, and Genevieve Z. Steiner	
47	Content Analysis: Using Critical Realism to Extend Its Utility ..	827
	Doris Y. Leung and Betty P. M. Chung	
48	Thematic Analysis	843
	Virginia Braun, Victoria Clarke, Nikki Hayfield, and Gareth Terry	
49	Narrative Analysis	861
	Nicole L. Sharp, Rosalind A. Bye, and Anne Cusick	
50	Critical Discourse/Discourse Analysis	881
	Jane M. Ussher and Janette Perz	
51	Schema Analysis of Qualitative Data: A Team-Based Approach	897
	Frances Rapport, Patti Shih, Mia Bierbaum, and Anne Hogden	
52	Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses	917
	Pat Bazeley	
53	Sequence Analysis of Life History Data	935
	Bram Vanhoutte, Morten Wahrendorf, and Jennifer Prattley	
54	Data Analysis in Quantitative Research	955
	Yong Moon Jung	
55	Reporting of Qualitative Health Research	971
	Allison Tong and Jonathan C. Craig	
56	Writing Quantitative Research Studies	985
	Ankur Singh, Adyya Gupta, and Karen G. Peres	
57	Traditional Academic Presentation of Research Findings and Public Policies	999
	Graciela Tonon	
58	Appraisal of Qualitative Studies	1013
	Camilla S. Hanson, Angela Ju, and Allison Tong	

59	Critical Appraisal of Quantitative Research	1027
	Rocco Cavaleri, Sameer Bhole, and Amit Arora	
60	Appraising Mixed Methods Research	1051
	Elizabeth J. Halcomb	
Section II	Innovative Research Methods in Health Social Sciences	1069
61	Innovative Research Methods in Health Social Sciences: An Introduction	1071
	Pranee Liamputtong	
62	Personal Construct Qualitative Methods	1095
	Viv Burr, Angela McGrane, and Nigel King	
63	Mind Maps in Qualitative Research	1113
	Johannes Wheeldon and Mauri Ahlberg	
64	Creative Insight Method Through Arts-Based Research	1131
	Jane Marie Edwards	
65	Understanding Health Through a Different Lens: Photovoice Method	1147
	Michelle Teti, Wilson Majee, Nancy Cheak-Zamora, and Anna Maurer-Batjer	
66	IMAGINE: A Card-Based Discussion Method	1167
	Ulrike Felt, Simone Schumann, and Claudia G. Schwarz-Plaschg	
67	Timeline Drawing Methods	1183
	E. Anne Marshall	
68	Semistructured Life History Calendar Method	1201
	Ingrid A. Nelson	
69	Calendar and Time Diary Methods	1219
	Ana Lucía Córdova-Cazar and Robert F. Belli	
70	Body Mapping in Research	1237
	Bronwyne Coetzee, Rizwana Roomaney, Nicola Willis, and Ashraf Kagee	
71	Self-portraits and Maps as a Window on Participants' Worlds ..	1255
	Anna Bagnoli	
72	Walking Interviews	1269
	Alexandra C. King and Jessica Woodroffe	
73	Participant-Guided Mobile Methods	1291
	Karen Block, Lisa Gibbs, and Colin MacDougall	

74	Digital Storytelling Method	1303
	Brenda M. Gladstone and Elaine Stasiulis	
75	Netnography: Researching Online Populations	1321
	Stephanie T. Jong	
76	Web-Based Survey Methodology	1339
	Kevin B. Wright	
77	Blogs in Social Research	1353
	Nicholas Hookway and Helene Snee	
78	Synchronous Text-Based Instant Messaging: Online Interviewing Tool	1369
	Gemma Pearce, Cecilie Thøgersen-Ntoumani, and Joan L. Duda	
79	Asynchronous Email Interviewing Method	1385
	Mario Brondani and Rodrigo Mariño	
80	Cell Phone Survey	1403
	Lilian A. Ghandour, Ghinwa Y. El Hayek, and Abba Mehio Sibai	
81	Phone Surveys: Introductions and Response Rates	1417
	Jessica Broome	
82	The Freelist Method	1431
	Marsha B. Quinlan	
83	Solicited Diary Methods	1447
	Christine Milligan and Ruth Bartlett	
84	Teddy Diaries: Exploring Social Topics Through Socially Saturated Data	1465
	Marit Halder and Randi Wærdahl	
85	Qualitative Story Completion: A Method with Exciting Promise	1479
	Virginia Braun, Victoria Clarke, Nikki Hayfield, Naomi Moller, and Irmgard Tischner	

Volume 3

Section III Doing Cross-Cultural Research in Health Social

Sciences	1497
86 Doing Cross-Cultural Research: An Introduction	1499
Pranee Liamputtong	
87 Kaupapa Māori Health Research	1507
Fiona Cram	

88	Culturally Safe Research with Vulnerable Populations (Māori)	1525
	Denise Wilson	
89	Using an Indigenist Framework for Decolonizing Health Promotion Research	1543
	Karen McPhail-Bell, Alison Nelson, Ian Lacey, Bronwyn Fredericks, Chelsea Bond, and Mark Brough	
90	Engaging Aboriginal People in Research: Taking a Decolonizing Gaze	1563
	Emma Webster, Craig Johnson, Monica Johnson, Bernie Kemp, Valerie Smith, and Billie Townsend	
91	Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women	1579
	Chijioke Obasi	
92	Researcher Positionality in Cross-Cultural and Sensitive Research	1601
	Narendar Manohar, Pranee Liamputtong, Sameer Bhole, and Amit Arora	
93	Considerations About Translation: Strategies About Frontiers	1617
	Lía Rodríguez de la Vega	
94	Finding Meaning: A Cross-Language Mixed-Methods Research Strategy	1639
	Catrina A. MacKenzie	
95	An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups	1653
	Caroline Elizabeth Fryer	
96	The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research	1675
	Sara Stevano and Kevin Deane	
97	Indigenous Statistics	1691
	Tahu Kukutai and Maggie Walter	
98	A Culturally Competent Approach to Suicide Research with Aboriginal and Torres Strait Islander Peoples	1707
	Monika Ferguson, Amy Baker, and Nicholas Procter	
99	Visual Methods in Research with Migrant and Refugee Children and Young People	1723
	Marta Moskal	
100	Participatory and Visual Research with Roma Youth	1739
	Oana Marcu	

101	Drawing Method and Infant Feeding Practices Among Refugee Women	1757
	June Joseph, Pranee Liamputtong, and Wendy Brodribb	
102	Understanding Refugee Children's Perceptions of Their Well-Being in Australia Using Computer-Assisted Interviews	1777
	Jeanette A. Lawrence, Ida Kaplan, and Agnes E. Dodds	
103	Conducting Focus Groups in Terms of an Appreciation of Indigenous Ways of Knowing	1795
	Norma R. A. Romm	
104	Visual Depictions of Refugee Camps: (De)constructing Notions of Refugee-ness?	1811
	Caroline Lenette	
105	Autoethnography as a Phenomenological Tool: Connecting the Personal to the Cultural	1829
	Jayne Pitard	
106	Ethics and Research with Indigenous Peoples	1847
	Noreen D. Willows	
107	Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds	1871
	Anna Ziersch, Clemence Due, Kathy Arthurson, and Nicole Loehr	
108	Ethical Issues in Cultural Research on Human Development ...	1891
	Namrata Goyal, Matthew Wice, and Joan G. Miller	
Section IV Sensitive Research Methodology and Approach: Researching with Particular Groups in Health Social Sciences		1905
109	Sensitive Research Methodology and Approach: An Introduction	1907
	Pranee Liamputtong	
110	"With Us and About Us": Participatory Methods in Research with "Vulnerable" or Marginalized Groups	1919
	Jo Aldridge	
111	Inclusive Disability Research	1935
	Jennifer Smith-Merry	
112	Understanding Sexuality and Disability: Using Interpretive Hermeneutic Phenomenological Approaches	1953
	Tinashe Dune and Elias Mpofu	

113	Ethics and Practice of Research with People Who Use Drugs . . .	1973
	Julaine Allan	
114	Researching with People with Dementia	1991
	Jane McKeown	
115	Researching with Children	2007
	Graciela Tonon, Lia Rodriguez de la Vega, and Denise Benatuil	
116	Optimizing Interviews with Children and Youth with Disability	2023
	Gail Teachman	
117	Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization	2041
	Kat Kolar and Farah Ahmad	
118	Capturing the Research Journey: A Feminist Application of Bakhtin to Examine Eating Disorders and Child Sexual Abuse	2061
	Lisa Hodge	
119	Feminist Dilemmas in Researching Women's Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise	2079
	Lizzie Seal	
120	Animating Like Crazy: Researching in the Animated Visual Arts and Mental Welfare Fields	2093
	Andi Spark	
121	Researching Underage Sex Work: Dynamic Risk, Responding Sensitive, and Protecting Participants and Researchers	2111
	Natalie Thorburn	
122	The Internet and Research Methods in the Study of Sex Research: Investigating the Good, the Bad, and the (Un)ethical	2127
	Lauren Rosewarne	
123	Emotion and Sensitive Research	2145
	Virginia Dickson-Swift	
124	Doing Reflectively Engaged, Face-to-Face Research in Prisons: Contexts and Sensitivities	2163
	James E. Sutton	
125	Police Research and Public Health	2179
	Jyoti Belur	

126	Researching Among Elites	2197
	Neil Stephens and Rebecca Dimond	
127	Eliciting Expert Practitioner Knowledge Through Pedagogy and Infographics	2213
	Robert H. Campbell	
Index		2225

About the Editor



Pranee Liamputtong is a medical anthropologist and Professor of Public Health at the School of Science and Health, Western Sydney University, Australia. Previously, Pranee held a Personal Chair in Public Health at the School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University, Melbourne, Australia, until January 2016. She has also previously taught in the School of Sociology and Anthropology and worked as a Public Health Research Fellow at the Centre for the Study of Mothers' and Children's Health, La Trobe University. Pranee has a particular interest in issues related to cultural and social influences on childbearing, childrearing, and women's reproductive and sexual health. She works mainly with refugee and migrant women in Melbourne and with women in Asia (mainly in Thailand, Malaysia, and Vietnam). She has published several books and a large number of papers in these areas.

Some of her books in the health and social sciences include *The Journey of Becoming a Mother Among Women in Northern Thailand* (Lexington Books, 2007); *Population Health, Communities and Health Promotion* (with Sansnee Jirojwong, Oxford University Press, 2009); *Infant Feeding Practices: A Cross-Cultural Perspective* (Springer, 2011); *Motherhood and Postnatal Depression: Narratives of Women and Their Partners* (with Carolyn Westall, Springer, 2011); *Health, Illness and Wellbeing: Perspectives and Social Determinants* (with Rebecca Fanany and Glenda Verrinder, Oxford University Press, 2012); *Women, Motherhood and Living with HIV/AIDS: A Cross-Cultural Perspective* (Springer, 2013); *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural*

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Pranee is a Qualitative Researcher and has also published several method books. Her most recent method books include *Researching the Vulnerable: A Guide to Sensitive Research Methods* (Sage, 2007); *Performing Qualitative Cross-Cultural Research* (Cambridge University Press, 2010); *Focus Group Methodology: Principle and Practice* (Sage, 2011); *Qualitative Research Methods, 4th Edition* (Oxford University Press, 2013); *Participatory Qualitative Research Methodologies in Health* (with Gina Higginbottom, Sage, 2015); and *Research Methods in Health: Foundations for Evidence-Based Practice*, which is now in its third edition (Oxford University Press, 2017).

About the Contributors

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Stewart Anderson is a Professor of Biostatistics and Clinical and Translational Medicine at the University of Pittsburgh, Graduate School of Public Health.

His areas of current methodological research interests include (1) general methodology in longitudinal and survival data analysis, (2) modern regression techniques, and (3) methods in the design and analysis of clinical trials. He has over 25 years of experience in cancer clinical trial research in the treatment and prevention of breast cancer and in mental health in mid- to late-life adults.

Mike Armour is a Postdoctoral Research Fellow at NICM, Western Sydney University. Mike's research focus is on implementing experimental designs that can replicate complex clinical interventions that are often seen in the community. Mike has extensive experience in the design and conduct of clinical trials using a mixed-methods approach to help shape trial design, often including clinicians and community groups.

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Kathy Arthurson is the Director of Neighborhoods, Housing and Health at Flinders Research Unit, Flinders University of South Australia. Her past experiences as a Senior Policy Analyst in a range of positions including public health, housing, and urban policy are reflected in the nature of her research, which is applied research grounded in broader concepts concerning social inclusion, inequality, and social justice.

Anna Bagnoli is an Associate Researcher in the Sociology Department of the University of Cambridge. Anna has a distinctive interest in methodological innovation and in visual, arts-based, and other creative and participatory approaches. She teaches postgraduates on qualitative analysis and CAQDAS and supervises postgraduates engaged with qualitative research projects. Her current work looks at the identity processes of migrants, with a focus on the internal migrations of Europeans, particularly young Italians.

Amy Baker is an academic in the Occupational Therapy Program at the University of South Australia. Her teaching and research focuses on mental health and suicide prevention, particularly working with people of culturally and linguistically diverse backgrounds and research approaches that are qualitative and participatory in nature.

Ruth Bartlett is an Associate Professor based in the Faculty of Health Sciences, University of Southampton, with a special interest in people with dementia and participatory research methods. Ruth has designed and conducted several funded research projects using innovative qualitative techniques, including diary and visual methods. Ruth has published widely in the health and social sciences and teaches and supervises postgraduate students.

Pat Bazeley has 25 years' experience in exploring, teaching, and writing about the use of software for qualitative and mixed-methods analysis for social and health research. Having previously provided training, consulting, and retreat facilities to researchers through Research Support P/L, she is now focusing on writing and

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Robert F. Belli is a Professor of Psychology at the University of Nebraska–Lincoln. He received his Ph.D. in Experimental Psychology from the University of New Hampshire. Robert's research interests focus on the role of memory in applied settings, and his published work includes research on autobiographical memory, eyewitness memory, and the role of memory processes in survey response. The content of his work in surveys focuses on methods that can improve retrospective reporting accuracy.

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Mia Bierbaum is a Research Assistant at Macquarie University's Centre for Healthcare Resilience and Implementation Science, within the Australian Institute of Health Innovation. Mia had worked on the Healthy Living after Cancer project, providing a coaching service for cancer survivors, and conducted population monitoring research to examine the perceptions of cancer risk factors and behavioral change for patients. Her interests include health systems enhancement, behavioral research, and the prevention of chronic disease.

Simon Bishop is an Associate Professor of Organizational Behavior at Nottingham University Business School and a founding member of the Centre for Health Innovation and Learning. His research focuses around the relationship between public policy, organizational arrangements, and frontline practice in healthcare. His work has been published in a number of leading organization and policy and

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Fiona Cram has tribal affiliations with Ngāti Pahauwera (Indigenous Māori, Aotearoa New Zealand) and is the mother of one son. She has over 20 years of Kaupapa Māori (by Māori, for Māori) research and evaluation experience with Māori (Indigenous peoples of Aotearoa New Zealand) tribes, organizations, and communities, as well as with government agencies, district health boards, and philanthropic organizations.

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Section I

Traditional Research Methods in Health and Social Sciences



Traditional Research Methods in Health and Social Sciences: An Introduction

1

Pranee Liamputtong

Contents

1	Introduction	3
2	About the Section	4
	References	7

Keywords

Research · Research approaches · Knowledge · Evidence · Qualitative research · Quantitative research · Mixed methods research

1 Introduction

Acquiring knowledge through the use of research findings that were derived from the scientific method is the most objective way of knowing something. (Grinnell et al. 2014, p. 12)

Researchers conduct research in order to obtain knowledge that health and social care practitioners can use in the provision of health and social care programs to those in need. Knowledge can be cultivated in many ways. Cohen and Manion (2000) suggest that there are three primary forms of knowing: experience, reasoning, and research. However, for researchers, they generate new knowledge through research (Fawcett and Pockett 2015). In health and social care in particular, scientific research is seen to “yield the best source of evidence” (Schmidt and Brown 2015, p. 7). In order to provide evidence-based health care, research is conducted so that knowledge that addresses the practice concern can be obtained (Grove et al. 2013).

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3

Research has been referred to as a “planned and systematic activity” (Schmidt and Brown 2015, p. 14) that results in the construction of new knowledge that can be used to provide answers to some health problems or as evidence for health care practice (Polit and Beck 2011; Liamputtong and Schmied 2017). Traditionally, there are three main research approaches that health and social science researchers have adopted in their research. They are known as a qualitative, a quantitative, and a mixed methods research approach (Babbie 2016; Bryman 2016; Liamputtong 2017; Creswell and Plano Clark 2018). To put it simply, qualitative research approaches yield “qualitative data in the form of text” whereas quantitative research methods offer “quantitative data in the form of numbers” (Grinnell et al. 2014, p. 20). For the mixed methods research, both forms of data are included (Creswell and Plano Clark 2018).

Researchers need to make a decision what type of knowledge they need to generate, which will allow them to decide about the research method that is appropriate to their research questions (Liamputtong and Schmied 2017).

The word “research,” according to Walter (2013, p. 4), “evokes a popular imagery of a scholarly endeavour pursue using complicated formulas, and uninterpretable language and techniques.” Due to this perception, research can be seen as “far removed from our everyday lives and our social world.” But as readers will see in the section, not all research is like that. This is particularly research in the health and social science areas. Research, as Walter (2013, p. 4) points out, “is everywhere, and it touches many aspects of our social lives.” Readers can witness this in all chapters in the section (as well as those in other sections of the Handbook).

2 About the Section

Research, as defined by the Australian Research Council (2015, p. 9), is “the creation of new knowledge” as well as “the use of existing knowledge in a new and creative way” in order to obtain novel understandings, concepts, methodologies, and inventions. Research can also encompass “synthesis and analysis of previous research to the extent that it leads to new and creative outcomes.” This definition is clearly reflected in the section of the Handbook.

The section on traditional research methods in health and social sciences comprises four parts. It is the largest section within the Handbook. Section 1 is an introduction to research approaches and it comprises four chapters. Pranee Liamputtong introduces the nature of the qualitative inquiry that health and social science researchers can use (► Chap. 2, “Qualitative Inquiry”). Leigh Wilson provides discussions regarding the quantitative approach in health research (► Chap. 3, “Quantitative Research”). Cara Meixner and John Hathcoat write about the nature of mixed methods research (► Chap. 4, “The Nature of Mixed Methods Research”). The last chapter in this part is about the recruitment of research participants and was written by Narendar Manohar, Freya MacMillan, Genevieve Steiner and Amit Arora (► Chap. 5, “Recruitment of Research Participants”).

Section 2 contains a number of chapters that discuss the philosophical foundations and methodological frameworks that have been adopted in the health and social sciences. It contains 17 chapters. John Hathcoat, Cara Meixner, and Marck Nicholas provide in-depth discussion about ontology and epistemology that underpins the research approaches in health social science areas (► [Chap. 6, “Ontology and Epistemology”](#)). This chapter is followed by several chapters that dedicate to different epistemological approaches in the health social sciences. Viv Burr writes about the social constructionism (► [Chap. 7, “Social Constructionism”](#)), while Anastasia Marinopoulou provides discourses about the critical theory (► [Chap. 8, “Critical Theory: Epistemological Content and Method”](#)). Priya Khanna offers readers ideas about positivism and realism that underpins quantitative approaches (► [Chap. 9, “Positivism and Realism”](#)). In the next four chapters, the authors provide great insights into the methodological frameworks that most qualitative researchers have adopted: symbolic interactionism by Michael Carter and Andrea Alvarado (► [Chap. 10, “Symbolic Interactionism as a Methodological Framework”](#)); hermeneutics by Suzanne D’Souza (► [Chap. 11, “Hermeneutics: A Boon for Cross-Disciplinary Research”](#)); a feminist pragmatic model by Claudia Gillberg (► [Chap. 12, “Feminism and Healthcare: Toward a Feminist Pragmatist Model of Healthcare Provision”](#)); and critical ethnography by Patti Shih (► [Chap. 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology”](#)).

Eric Leake offers readers a novel methodological framework in social research, what he refers to as empathy (► [Chap. 14, “Empathy as Research Methodology”](#)). The Indigenist and decolonizing research methodology is written by Elizabeth Rix and colleagues (► [Chap. 15, “Indigenist and Decolonizing Research Methodology”](#)). Rona Pillay confers ideas about ethnomethodology (► [Chap. 16, “Ethnomethodology”](#)) and Elena Wilson writes about the community-based participatory action research (► [Chap. 17, “Community-Based Participatory Action Research”](#)). Linda Belgrave and Kapriskie Seide deliberate in great details about the grounded theory methodology (► [Chap. 18, “Grounded Theory Methodology: Principles and Practices”](#)). Case study research is written by Pota Forrest-Lawrence (► [Chap. 19, “Case Study Research”](#)). Two chapters on evaluation are conferred by Angela Dawson (► [Chap. 20, “Evaluation Research in Public Health”](#)) and Gary Kreps and Jordan Alpert (► [Chap. 21, “Methods for Evaluating Online Health Information Systems”](#)). In the last chapter in this part, it is about translational research that has become an increasingly important in the health sciences and is written by Lynn Kemp (► [Chap. 22, “Translational Research: Bridging the Chasm Between New Knowledge and Useful Knowledge”](#)).

Section 3 of this section dedicates to the ways researchers in the health social sciences collect their empirical materials. It is divided into three sub-parts. In the first sub-part, chapters involved data collection methods in qualitative research. Sally Nathan and colleagues examine the qualitative interviewing method that has been popularly adopted in qualitative research projects (► [Chap. 23, “Qualitative Interviewing”](#)). Narrative research is offered by Kay Ntinda (► [Chap. 24, “Narrative Research”](#)), and the life history interview by Erin Jessee (► [Chap. 25, “The Life History Interview”](#)). Two chapters concerning ethnography are discussed by two

authors: Bonnie Pang on the ethnographic method (► [Chap. 26, “Ethnographic Method”](#)) and Michelle LaFrance on the institutional ethnography (► [Chap. 27, “Institutional Ethnography”](#)). Sarah White provides insights into the conversation analysis (► [Chap. 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”](#)) whereas Raymond Lee discusses issues relating to the unobtrusive methods (► [Chap. 29, “Unobtrusive Methods”](#)). A great insight about autoethnography is written by Anne Bunde-Birouste and colleagues (► [Chap. 30, “Autoethnography”](#)). The last chapter in this sub-part is the feminist-based method of memory work discussed by Lia Bryant and Katerina Bryant (► [Chap. 31, “Memory Work”](#)).

In the quantitative approach and practice sub-part, authors offer knowledge about different types of quantitative methods. Megan Mhaka and Roy Tapera discuss issues surrounding the traditional survey and questionnaire platforms (► [Chap. 32, “Traditional Survey and Questionnaire Platforms”](#)). Kate McBride and colleagues provide good insights into epistemology in health research (► [Chap. 33, “Epidemiology”](#)). Single-case designs are written by Breanne Byiers (► [Chap. 34, “Single-Case Designs”](#)) and longitudinal study designs by Stewart Anderson (► [Longitudinal Study Designs](#)). Martin Howell and Kirsten Howard confer the discrete choice experiments (► [Chap. 36, “Eliciting Preferences from Choices: Discrete Choice Experiments”](#)) whereas Mike Armour and colleagues discuss the randomized controlled trials (► [Chap. 37, “Randomized Controlled Trials”](#)). The last chapter in his sub-part is about measurement issues in quantitative research written by Dafna Merom and James Rufus John (► [Chap. 38, “Measurement Issues in Quantitative Research”](#)).

The last sub-part on research methods includes chapters that discuss the multi-methods, mixed methods, collaborative research, and systematic reviews. There are eight chapters in this sub-part. Graciela Tonon reviews the use of integrated methods in research (► [Chap. 39, “Integrated Methods in Research”](#)), while Kate McBride and colleagues address the use of mixed methods in research (► [Chap. 40, “The Use of Mixed Methods in Research”](#)). The Delphi technique is conferred by Jane Chalmers and Mike Armour (► [Chap. 41, “The Delphi Technique”](#)). Karine Manera and colleagues discuss the nominal group technique (► [Chap. 42, “Consensus Methods: Nominal Group Technique”](#)), and Tinashe Dune and colleagues tell us about the Q methodology that researchers use to examine human subjectivity (► [Chap. 43, “Jumping the Methodological Fence: Q Methodology”](#)). Social network analysis is written by Janet Long and Simon Bishop (► [Chap. 44, “Social Network Research”](#)). The last two chapters in this sub-part contain a systematic review of literature as a research method. Angela Dawson provides great insights into the meta-synthesis of qualitative literature (► [Chap. 45, “Meta-Synthesis of Qualitative Research”](#)) while Freya MacMillan and colleagues do so for the systematic review method (► [Chap. 46, “Conducting a Systematic Review: A Practical Guide”](#)).

The last part of this section comprises chapters that discuss how to make sense of the research data, research representation, and evaluation of research. Doris Leung and Betty Chung confer content analysis (► [Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility”](#)) whereas Virginia Braun and colleagues

provide great insights into the thematic analysis method (► Chap. 48, “Thematic Analysis”). Nicole Sharp and Rosaline Bye write about how to analyze data from the narrative research (► Chap. 49, “Narrative Analysis”), and Jane Ussher and Janette Perz suggest ways that researchers can adopt the critical discourse analysis in research (► Chap. 50, “Critical Discourse/Discourse Analysis”). The schema analysis of qualitative data, a team-based approach, is written by Frances Rapport and colleagues (► Chap. 51, “Schema Analysis of Qualitative Data: A Team-Based Approach”). Patricia Bazeley provides great discussions and details about using qualitative data analysis software (QDAS) to assist data analyses (► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). The chapter sequence analysis of life history data is written by Bram Vanhoutte, Morten Wahrendorf, and Jennifer Prattley (► Chap. 53, “Sequence Analysis of Life History Data”). Yong Moon Jung explains how researchers can analyze quantitative data (► Chap. 54, “Data Analysis in Quantitative Research”). The next few chapters are dedicated to the reporting of research findings. Allison Tong and Jonathan Craig write about reporting of qualitative health research (► Chap. 55, “Reporting of Qualitative Health Research”), while Ankur Singh and colleagues confer the way that quantitative research studies can be written up (► Chap. 56, “Writing Quantitative Research Studies”). Graciela Tonon tells us about a traditional academic presentation of research findings and public policies (► “Traditional Academic Presentation of Research Findings and Public Policies”). The last three chapters in this part are about the appraisal of a research study. Camilla Hanson and colleagues discuss critical appraisal of qualitative studies (► Chap. 58, “Appraisal of Qualitative Studies”) while Rocco Cavaleri and colleagues do so for the appraisal of quantitative research (► Chap. 59, “Critical Appraisal of Quantitative Research”). The very last chapter in this part is written by Elizabeth Halcomb, who provides explanations about appraising mixed methods research (► Chap. 60, “Appraising Mixed Methods Research”).

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Qualitative Inquiry

2

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Contents

1	Introduction	10
2	Why Qualitative Inquiry	12
3	Qualitative Researchers	14
4	Qualitative Inquiry: The Distinctiveness	14
4.1	Theory Generation: Inductive Approach	15
4.2	Framing the Study: Methodological Frameworks	16
4.3	“Data Enhancers”: Qualitative Data Collection Methods	17
4.4	The Source of Data: Research Participants, Sampling Strategy, and Saturation Concept	18
4.5	Qualitative Research and Trustworthiness	19
4.6	Making Sense of Qualitative Data: Analytic Strategies	20
5	Conclusion and Future Directions	21
	References	22

Abstract

This chapter discusses the nature of the qualitative inquiry. Qualitative inquiry refers to “a broad approach” that qualitative researchers adopt as a means to examine social circumstances. The inquiry is based on an assumption which posits that people utilize “what they see, hear, and feel” to make sense of social experiences. There are many features that differentiate qualitative inquiry from the quantitative approach. Fundamentally, it is interpretive. The meanings and interpretations of the participants are the essence of qualitative inquiry. Qualitative researchers can be perceived as constructivists who attempt to find answers in the real world. Fundamentally, qualitative researchers look for meanings that people have constructed. Qualitative research is valuable in many ways. It offers

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researchers to hear silenced voices, to work with marginalized and vulnerable people, to address social justice issues, and to contribute to the person-centered healthcare and the design of clinical trials. The chapter discusses in great depth the distinctive features of the qualitative inquiry. In particular, it includes the inductive nature of qualitative research, methodological frameworks, purposive sampling technique, saturation concept, qualitative data analysis, and the trustworthiness of a qualitative study.

Keywords

Qualitative inquiry · Meaning and interpretation · Qualitative researcher · Methodological framework · Saturation · Trustworthiness

1 Introduction

Qualitative inquiry seeks to discover and to describe narratively what particular people do in their everyday lives and what their actions mean to them. It identifies meaning-relevant *kinds* of things in the world—kinds of people, kinds of actions, kinds of beliefs and interests—focusing on differences in forms of things that make a difference for meaning. (Erikson 2018, p. 36, original emphasis)

Qualitative inquiry refers to “a broad approach” that qualitative researchers adopt as a means to examine social circumstances. The inquiry is based on an assumption which posits that people utilize “what they see, hear, and feel” to make sense of social experiences (Rossman and Rallis 2017, p. 5). Fundamentally, qualitative research contributes to the social inquiry which aims to interpret “the meanings of human actions” (Bradbury-Jones et al. 2017, p. 627). It is a type of research that embodies individuals as the “whole person living in dynamic, complex social arrangements” (Rogers 2000, p. 51).

The word “qualitative” derives from the Latin word “*qualitas*”, which pertains to “a primary focus on the qualities, the features, of entities” (Erikson 2018, p. 36). In contrast, the word “quantitative” is from the word “*quantitas*” which relates to “a primary focus on differences in amount” (Erikson 2018, p. 36). The term qualitative, according to Denzin and Lincoln (2011, p. 8), has its focus on “the qualities of entities” as well as on “processes and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity, or frequency.”

Qualitative inquiry, according to Rossman and Rallis (2017, p. 5), is grounded in “empiricism,” the philosophical tradition which theorizes that “knowledge is obtained by direct experience through the physical senses.” Aristotle, one of the first qualitative researchers, attempted to interpret things in the world by listening and watching. He theorized that ideas that we have are concepts that are derived from our experiences with actual beings, objects, and events. This is what qualitative researchers do. Often, qualitative researchers work closely with individuals, and they listen attentively on what the participants say, probe further, and try to make sense of what the participants tell them.

Qualitative inquiry has its focus on the social world. The qualitative research approach, according to Hesse-Biber (2017, p. 4), offers “a unique grounding position” for researchers to undertake research that “fosters particular ways of asking questions” and “provides a point of view onto the social world,” which in turn will help researchers “to obtain understanding of a social issue or problem that privileges subjective and multiple understandings.” Qualitative research offers “explanations for objects or social actions” (Rossman and Rallis 2017, p. 8). In the social world, we deal with the subjective experiences of individuals. In different social situations and over time, people’s “understanding of reality” can change (Dew 2007, p. 434). This makes qualitative research different from researching the natural world, which can be treated as “objects or things” (Taylor et al. 2016). In order to capture and understand the perspectives of individuals, qualitative inquiry relies heavily on words or stories that these individuals tell researchers (Liamputtong 2013; Patton 2015; Creswell and Poth 2018). Thus, qualitative research has also been recognized as “the word science” (Denzin 2008; Liamputtong 2017).

According to Yin (2016), Marshall and Rossman (2016), Taylor et al. (2016), Tolley (2016), Rossman and Rallis (2017), and Creswell and Poth (2018), there are common features of qualitative inquiry. These are presented in Table 1.

Qualitative research traverses many fields and disciplines (Denzin and Lincoln 2018). Qualitative research has been adopted extensively in the social sciences, particularly in anthropology and sociology. We have also witnessed the wider adoption of a qualitative approach in criminology, social work, education, nursing, and even psychology and medicine. In the past decade or so, qualitative data or interpretive information has been gradually accepted as a crucial component in our understanding of health (Green and Thorogood 2014; Liamputtong 2016, 2017). In public health, particularly the new public health that recognizes the need to “understand” people, Baum (2016, p. 201) suggests that qualitative research is needed since

Table 1 Common features of qualitative inquiry

Qualitative inquiry: Common features
<ul style="list-style-type: none"> • It is fundamentally interpretive • The meanings and interpretation of the participants is the essence of qualitative inquiry • It asks why, how, and under what circumstance things arise • It explicitly attends to and account for the contextual conditions of the participants • It takes place in the natural settings of human life • It emphasizes holistic accounts and multiple realities • It is situated within some methodological frameworks • It makes use of multiple methods • It is emergent rather than rigidly predetermined • Participants are treated as an active respondents rather than as subject • The researcher is the means through which the research is undertaken.

it offers “considerable strength in understanding and interpreting complexities” of people’s behavior and their health issues (see Liamputtong 2016).

Readers may notice that qualitative research is often used interchangeably with the term “qualitative inquiry.” Dimitriadis (2016) suggests that the word “research” should be replaced with the word “inquiry.” He argues that the word “research” is “tainted by a lingering positivism.” This is the consequence of the paradigm wars operating within the influence of evidence-based practices in medicine that has treated qualitative research badly (Liamputtong 2016, 2017; Torrance 2017; Denzin 2018). Instead, inquiry “implies an open-endedness, uncertainty, ambiguity, praxis, pedagogies of liberation, freedom, [and] resistance” (Denzin and Lincoln 2018, p. 11). I will mainly use the term qualitative inquiry in this chapter, but occasionally, I will also use the term qualitative research.

2 Why Qualitative Inquiry

Readers might ask why should researchers use qualitative inquiry in their research. Creswell and Poth (2018, p. 45) contend that qualitative research is adopted because there is a problem or issue that needs to be explored. This is particularly when “silenced voices” need to be heard or problems or issues cannot be “easily measured.” Qualitative inquiry permits researchers to ask questions, and to find answers, that can be difficult or impossible with the quantitative approach (Hesse-Biber 2017). For example, What makes many working-class men continue to smoke? Why do some health and social care programs do not work? What makes some of these programs succeed? Why are screening programs underused? What contributes to stigma and discrimination in the local areas despite extensive media and educational campaigns in the country? Why do women with low incomes put motherhood before marriage? How do single mothers confront their social and economic challenges? How do young refugee people deal with social isolation? How do migrant mothers deal with infant feeding practices in their new social environment? These are some examples of what qualitative research can find answers for health and social care policy-makers and professionals.

According to Yin (2016, p. 3), every real-world issue can be examined by the qualitative inquiry. These real-world issues are what Patton (2015) refers to as “stuff.” Yin writes:

Stuff happens everywhere. Qualitative inquiry documents the stuff that happens among real people in the real world in their own words, from their own perspectives, and within their own contexts; it then makes sense of the stuff that happens by finding patterns and themes among the seeming chaos and idiosyncrasies of lots of stuff.

Qualitative research is essentially crucial for research involving marginalized, vulnerable, or hard-to-reach individuals and communities (Liamputtong 2007, 2010; Taylor et al. 2016; Flick 2018). This is particularly so when they are “too small to become visible” in quantitative research (Flick 2018, p. 452; Greenhalgh et al. 2016;

Yin 2016). More importantly, due to their marginalized, vulnerable status, and distrust in research, most of these individuals tend to decline to participate in research. The nature of qualitative inquiry will permit qualitative researchers to be able to engage with these individuals. In their qualitative research (using life history narratives and intersubjective dialogue) with previously incarcerated HIV-positive women in Alabama, Sprague et al. (2017, p. 725) tell us that:

The qualitative design and accompanying methods applied in this study enabled us to explore the timing, sequence, and import of life events and behaviors driving risk for HIV and incarceration—while grounding these realities firmly in their unique social context to foster a greater understanding of women’s lived experiences. These methods allowed for exploring the interaction and intersection between different variables, such as abuse and drug use, across the life course. Such interaction effects are poorly controlled for in more quantitative or modeling approaches. . . Qualitative research methods are uniquely able to wrestle with multiple social structural factors and influences in ways that remain unmatched by other research methods.

We have also witnessed the rise of qualitative inquiry in research relating to the social justice issues (see Denzin and Lincoln 2011; Taylor et al. 2016; Daniels et al. 2017). However, this trend has also been practiced by many social scientists in the past. Becker (1967), in his piece “*Whose Side Are We On?*,” discussed the role of social scientists in presenting the voices of some marginalized groups of people. Becker contended that “since powerful people have many means at their disposal to present their versions of reality, we should side with society’s underdogs, the powerless” (Taylor et al. 2016, p. 26). C Wright Mills (1959) believed that it is the political responsibility of social scientists to help individuals to understand their “personal troubles,” which are also “social issues” that confronted others in the society as well.

Qualitative research has increasingly received interest in the patient-centered care and evidence-based practice in healthcare (Olson et al. 2016). This is mainly because qualitative inquiry can cultivate great understanding of the beliefs, attitudes, and behaviors of the patients and consumers (Liamputtong 2013, 2016, 2017; Olson et al. 2016; Thirsk and Clark 2017). These in-depth understanding will permit health professionals to better accommodate health interventions to suit the needs of the consumers (Yardley et al. 2015). In the areas of HIV/AIDS, for example, HIV/AIDS is a global public health concern, and antiretroviral therapy (ART) has saved many lives worldwide. However, nonadherence to ART is still a huge issue in most parts of the world (Liamputtong et al. 2015; Fields et al. 2017). Sankar et al. (2006, p. S54) contend that qualitative research can contribute greatly to our understanding of the nonadherence of combination antiretroviral therapy (ART). Qualitative inquiry provides a unique means for understanding the complex factors that influence adherence (see Sankar et al. 2006; Liamputtong et al. 2015; Fields et al. 2017).

According to Sankar et al. (2006), qualitative inquiry offers persuasive means for exploring adherence to ART. Often, there are many factors that influence adherence among individuals including culture, stigma, medication beliefs, and access. Sankar et al. (2006, p. S54) argue that “a disregard for the social and cultural context of adherence or the imposition of adherence models inconsistent with local values and

practices is likely to produce irrelevant or ineffective interventions.” Sankar et al. (2006, p. S65) also contend that thus far qualitative research has been essential in studies concerning ART adherence as it has unfolded “key features and behaviors that could not have been identified using quantitative methods alone” (see Liamputtong et al. 2015).

Qualitative research can contribute effectively to the design of clinical trials in healthcare (Duggleby and Williams 2016; Russell et al. 2016; Toye et al. 2016). Qualitative inquiry helps trial researchers to know their trial participants better. It can also help the researchers to comprehend the successes and failure of trial interventions, which can save money on trials that might not work (Toye et al. 2016). Essentially, the qualitative inquiry can “show the human faces behind the numbers, providing critical context when interpreting statistical outcomes,” as well as make sure that “the numbers can be understood as constituting meaningful changes in the lives of real people” (Patton 2015, p. 179).

3 Qualitative Researchers

Fundamentally, qualitative researchers look for meanings that people have constructed (Taylor et al. 2016; Hesse-Biber 2017; Denzin and Lincoln 2018). They are interested in learning about “how people make sense of their world and the experiences they have in the world” (Merriam and Tisdell 2016, p. 15). Qualitative researchers can be perceived as “constructivists” who “seek answers to their questions in the real world” (Rossman and Rallis 2017, p. 4) and then “interpret what they see, hear, and read in the worlds around them” (p. 5).

Qualitative researchers are individuals who commit themselves to several issues. Figure 1 presents the characteristics of qualitative researchers.

Qualitative researchers are also seen as craftspersons (Taylor et al. 2016, p. 11). They are malleable in how they carry out their research. They are social scientists who are inspired to be a research methodologist who “deploy a wide range of interconnected interpretive practices, hoping always to get a better understanding of the subject matter at hand” (Denzin and Lincoln 2018, p. 10).

Qualitative inquiry is personal and sensitizes to personal biography as the researcher acts as “the instrument of inquiry” (Patton 2015, p. 3; Rossman and Rallis 2017, p. 9). What brings qualitative researchers to their research matters. Thus, qualitative researchers tend to acknowledge who they are and how their personal biography frames their research. They value their “unique perspective as a source of understanding rather than something to be cleansed from the study” (Rossman and Rallis 2017, p. 9). Qualitative research is an exquisite sensitivity to personal biography.

4 Qualitative Inquiry: The Distinctiveness

I have pointed out to general features of qualitative inquiry at the beginning. In the following sections, I will discuss some salient characteristics in more details.



Fig. 1 Salient characteristics of qualitative researchers

4.1 Theory Generation: Inductive Approach

Typically, qualitative research is inductive. The qualitative research adopts “a logic of ‘theory generation’ rather than ‘theory testing’” as practiced in quantitative research (Hesse-Biber 2017, p. 11; see also ► Chap. 3, “Quantitative Research”). Inductive reasoning will allow researchers to adopt particular understandings and develop a general conceptual understanding of the issue they examine (Babbie 2016; Taylor et al. 2016; Rossman and Rallis 2017).

Qualitative research projects typically commence with the collection of particular data and follow with the analysis that will allow the researchers to form a more general understanding of the issue they examine (Green and Thorogood 2014; Berger and Lorenz 2016; Merriam and Tisdell 2016; Hesse-Biber 2017). Thus, guiding questions that they use to collect their data are open-ended that permit allow multiple meanings to surface. Usually, the questions that researchers ask in qualitative research start with words like “how,” “why,” or “what” (Hesse-Biber 2017, p. 4), rather than questions about “how many” or “how much” (Green and Thorogood 2014, p. 5). For instance, How do women living with breast cancer cope with their health condition during chemotherapy treatment?, Why do many working mothers experience struggles to continue breastfeeding?, and What prejudice and discrimination that transwomen experience in their everyday life?

Nevertheless, despite being inductive, often qualitative researchers commence their study with some conceptual frameworks that shape their decisions in undertaking their research. However, this framework is adjustable. It can change as the study is being conducted (Rossman and Rallis 2017).

4.2 Framing the Study: Methodological Frameworks

Qualitative research tends to be situated within some methodological frameworks. Methodology determines a method for researchers to produce data for analysis (Taylor et al. 2016; Hesse-Biber 2017; Silverman 2017; Gaudet and Robert 2018). Avis (2003, p. 1003) contends that qualitative researchers need to provide their “methodological justification” by discussing the reason why they select a particular method in their research. The methods that researchers select and what they expect to get out of those methods is strongly formed by their “methodological position” (Dew 2007, p. 433).

A methodological framework provides “ways of seeing” (Morgan 1986, p. 12) in the conduct of qualitative research. Qualitative researchers must defend the adoption of their methods based on an appropriate methodological framework (Avis 2003; Taylor et al. 2016). It is not enough to say that we will use an in-depth interview in our research to examine the experience of living with chronic illness among our research participants. We must provide some framework to justify our method. In this case, we may say that we are interested in the lived experience of participants, and hence phenomenology will be our methodological framework, and with this type of research, an in-depth interview is appropriate because it will allow participants to tell their stories in great depth (Liamputtong 2013).

There are many methodological frameworks and research approaches practiced by qualitative researchers (Bradbury-Jones et al. 2017; Denzin and Lincoln 2018; Gaudet and Robert 2018). These include ethnography, symbolic interactionism, phenomenology, feminism, postmodernism, ethnomethodology, empathy, participatory action research, grounded theory, case study, and Indigenist methodology.

According to Hesse-Biber (2017, p.10), “the diversity of the methods with which qualitative researchers work is one of the distinguishing features of the qualitative landscape, which makes for a vast range of possible research topics and questions” (see also Bradbury-Jones et al. 2017; Denzin and Lincoln 2018). Bradbury-Jones et al. (2017, p. 628) suggest that the diversity of approaches that are available to qualitative researchers provides “a significant benefit” as it “provides a rich pool of methodological and technical options” that researchers can employ in their research.

In my own writing, I have advocated several methodological frameworks that qualitative researchers can draw on. These include ethnography, phenomenology, symbolic interactionism, hermeneutics, feminism, and postmodernism. Taylor et al. (2016) recommend several frameworks. These include phenomenology, symbolic interactionism, ethnomethodology, feminism, institutional ethnography, postmodernism, narrative analysis, and multi-sited, global research. In her recent book, Hesse-Biber (2017) suggests different methodological lenses including symbolic interactionism, dramaturgy, phenomenology, ethnomethodology, postmodernism, feminisms, critical race theory, and queer theory. Gaudet and Robert (2018) propose five frameworks: phenomenology, grounded theory, discourse analysis, narrative analysis, and ethnography (see also ► Chaps. 8, “Critical Theory: Epistemological Content and Method,” ► 10, “Symbolic Interactionism as a Methodological Framework,” ► 11, “Hermeneutics: A Boon for Cross-Disciplinary Research,”

► 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology,” ► 14, “Empathy as Research Methodology,” ► 16, “Ethnomethodology,” ► 15, “Indigenist and Decolonizing Research Methodology,” ► 17, “Community-Based Participatory Action Research,” and ► 27, “Institutional Ethnography”).

Different methodological frameworks offer different perspectives in the conduct of qualitative research (Silverman 2017). Each methodological framework may also be suitable for some research questions than others. Qualitative researchers must carefully consider which methodological framework will be more appropriate for their research project.

4.3 “Data Enhancers”: Qualitative Data Collection Methods

Qualitative research methods have been coined as “data enhancers” as they disclose “elements of empirical reality” which cannot be revealed by numbers (Neuman 2011; Berger and Lorenz 2016). All qualitative research methods attempt to obtain “rich, highly detailed accounts,” what Clifford Geertz (1973) refers to as “thick description” of a small number of people (Berger and Lorenz 2016).

Traditionally, there are a number of methods that qualitative researchers use to collect empirical materials in their research. These include in-depth interviewing method, focus group, life or oral history, and unobtrusive methods (see also ► Chaps. 23, “Qualitative Interviewing,” ► 25, “The Life History Interview,” and ► 29, “Unobtrusive Methods”). Among these methods, the in-depth interviewing method is the most commonly known technique and is widely employed by qualitative researchers (Minichiello et al. 2008; King and Horrocks 2010; Brinkmann and Kvale 2015; Serry and Liamputtong 2017). As Fontana and Frey (2000, p. 646) suggest, we reside in “an interview society.” Thus, interviews have become essential for individuals to make sense of people’s lives (Brinkmann and Kvale 2015).

In-depth interviewing method refers to “face-to-face encounter between the researcher and informants directed toward understanding informants’ perspectives on their experiences, or situations as expressed in their own words” (Taylor et al. 2016, p. 102). Gubrium et al. (2012) suggest that interviewing is a way of collecting empirical data about the social world of individuals by inviting them to talk about their lives in great depth. In an interview conversation, the researcher asks questions and then listens to what individuals say about their experiences such as their dreams, fears, and hopes. The researcher will then hear about their perspectives in their own words and learn about their family and social life and work (Kvale 2007; Brinkmann and Kvale 2015). Rubin and Rubin (2012, p. 3) say that in-depth interviewing “helps reconstruct events the researchers have never experienced.” It is particularly valuable when researchers wish to learn about the life of a wide range of individuals, “from illegal border crossing to becoming a paid assassin” (see also ► Chap. 23, “Qualitative Interviewing”).

There are other qualitative approaches that embody some forms of qualitative method. However, they are often referred to as the method (although some may refer them to as research traditions). These include the ethnographic method,

narrative research, grounded theory, memory work, autoethnography, case study, and participatory action research. It is not feasible to discuss all of these methods in this chapter. Readers can read more about them in the Qualitative Approaches and Practices in the handbook (see also ► Chaps. 24, “Narrative Research,” ► 26, “Ethnographic Method,” ► 27, “Institutional Ethnography,” ► 18, “Grounded Theory Methodology: Principles and Practices,” ► 30, “Autoethnography,” and ► 31, “Memory Work”).

4.4 The Source of Data: Research Participants, Sampling Strategy, and Saturation Concept

Qualitative research is concerned with the in-depth understanding of the issue or issues under examination; it thus relies heavily on individuals who are able to provide information-rich accounts of their experiences (Patton 2015; Yin 2016; Creswell and Poth 2018). This is referred to as the purposive sampling strategy (Liamputtong 2013; Houser 2015; Patton 2015; Bryman 2016; Yin 2016; Hesse-Biber 2017; Creswell and Poth 2018). Purposive sampling is a deliberate selection of specific individuals, events, or settings because of the crucial information they can provide, which cannot be obtained as adequately through other channels (Patton 2015; White 2015; Babbie 2016; Yin 2016; Creswell and Poth 2018). For example, in research that is concerned with how women with breast cancer deal with the side effects of chemotherapy treatment, purposive sampling will require the researcher to find women who have experienced the side effects of chemotherapy, instead of randomly selecting any cancer patients from an oncologist’s patient list. The purposive sample is also referred to as a “judgment sample” (Hesse-Biber 2017, p. 62). Research participants are selected to be included in a study due to their particular characteristics as determined by the particular objective of the research.

The powers of purposive sampling techniques, Patton (2015, p. 264, original emphasis) suggests, “lie in selecting *information-rich cases* for study in depth.” These information-rich cases are individuals or events or settings from which researchers can learn extensively about issues they wish to examine (Houser 2015; Liamputtong 2017; Creswell and Poth 2018).

The focus of decisions about sample size in qualitative research is on “flexibility and depth.” As I have suggested earlier, a fundamental concern of qualitative research is quality, not quantity. A qualitative research usually involves a small number of individuals. Qualitative research aims to examine the “meanings” or a “process” that individuals give to their own social situations. It does not require a generalization of the findings as in positivist science (Houser 2015; Hesse-Biber 2017). Qualitative research trades “breadth for depth” (Hesse-Biber 2017, p. 63). The important question to ask is whether the sample provides data that will allow the research questions or aims to be thoroughly addressed (Mason 2002; Green and Thorogood 2014; Houser 2015).

In qualitative research, there is no set formula that can be adopted to determine the sample size rigidly (Malterud et al. 2016). Often, at the commencement of the

research project, the number of participants to be recruited is not definitely known. However, data saturation, a concept associated with grounded theory, tends to be adopted by qualitative researchers to determine the number of research participants (see Hennink et al. 2017). Saturation is considered to occur when little or no new data is being generated (Padgett 2008; Liamputtong 2013; Green and Thorogood 2014; White 2015). O'Reilly and Parker (2012, p. 192) suggest that saturation is reached at "the point at which there are fewer surprises and there are no more emergent patterns in the data." The sample is adequate when "the emerging themes have been efficiently and effectively saturated with optimal quality data" (Carpenter and Suto 2008, p. 152) and when "sufficient data to account for all aspects of the phenomenon have been obtained" (Morse et al. 2002, p. 12).

Saturation is usually established during the data collection process (Houser 2015; Malterud et al. 2016). This means that in most qualitative research, data collection and data analysis tend to occur concurrently. This is the only way that researchers can know if they have reached saturation or not (Liamputtong 2013; Liamputtong and Serry 2017). Despite its usefulness, saturation has received some criticism, and many qualitative researchers have also questioned its use (see Morse 2015a). There are also different levels and types of saturation (see code saturation and meaning saturation discussed by Hennink et al. 2017). Due to space of the chapter, I encourage readers to refer to some of the references I have included here.

4.5 Qualitative Research and Trustworthiness

Qualitative research has criteria that can be used to evaluate the quality of the research. Within the qualitative approach, we use the term "rigor" or "trustworthiness," which refers to the quality of qualitative inquiry (Liamputtong 2013; Coleman and Unrau 2014; Morse 2015b; Bryman 2016; Marshall and Rossman 2016; Yin 2016; Rossman and Rallis 2017). A trustworthy research, according to Houser (2015, p. 146), is a research that researchers have "drawn the correct conclusions about the meaning of an event or phenomenon." In health research and practice in particular, trustworthiness means that "the findings must be authentic enough to allow practitioners to act upon them with confidence" (Raines 2011, p. 497).

Lincoln and Guba (1989) propose four criteria that many qualitative researchers have adopted to evaluate the trustworthiness of their qualitative research. The criteria were invented in responses to the influence of quantitative research that relies heavily on the issues of validity and reliability (Morse 2015b, 2018; see ► Chaps. 3, "Quantitative Research," and ► 38, "Measurement Issues in Quantitative Research"). These criteria include credibility, dependability, confirmability, and transferability.

Credibility relates to the question "how believable are the findings?" (Bryman 2016, p. 44). A credible study, according to Yin (2016, p. 85), refers to a study that "provides assurance that you have properly collected and interpreted the data, so the findings and conclusions accurately reflect and represent the world that was studied." Dependability focuses on "the consistency or congruency of the results" (Raines

2011, p. 456). It asks whether the research findings fit the data that have been collected (Carpenter and Suto 2008). Confirmability attempts to show that the findings and the interpretations of the findings do not derive from the imagination of the researchers but are clearly linked to the data.

Transferability (also referred to as applicability) begs the question of “to what degree can the study findings be *generalised* or applied to other individuals or groups, contexts, or settings?” or “do the findings apply to other contexts?” (Bryman 2016, p. 44). It attempts to establish the “generalisability of inquiry” (Tobin and Begley 2004, p. 392). Transferability in qualitative research emphasizes the theoretical or analytical generalizability of research findings. Transferability suggests that the theoretical knowledge that researchers obtained from qualitative research can be applied to other similar individuals, groups, or settings (Sandelowski 2004; Carpenter and Suto 2008; Padgett 2008). This is particularly so for research employing the ethnographic method and grounded theory research (see Gobo and Marciniak 2016; Wong et al. 2017; Creswell and Poth 2018; see also ► Chaps. 26, “Ethnographic Method,” and ► 18, “Grounded Theory Methodology: Principles and Practices”).

There are several strategies that qualitative researchers employ to ensure the rigor of their study. Often, these include prolonged engagement, persistent observation, thick description, peer review, member checking, external audits, triangulation, and reflexivity (Liamputtong 2013; Coleman and Unrau 2014; Morse 2015b; Rossman and Rallis 2017; Creswell and Poth 2018). Each of these strategies may not be suitable for all types of qualitative research, and some strategies may create difficulties for some qualitative projects than others (see Morse 2015b). Qualitative researchers need to take into account the type of qualitative method they use and social context on which their research is situated.

4.6 Making Sense of Qualitative Data: Analytic Strategies

As I have suggested, qualitative inquiry relies heavily on words and stories, how qualitative researchers make sense of their data also reflect this. Data analysis and interpretation of data are an exciting process that qualitative researchers bring meaning to the piles of data that they have gathered (Rossman and Rallis 2017, p. 227). It is a complex process and involves the following: “organizing the data, familiarizing with the data, identifying categories, coding the data, generating themes, interpreting, and searching for alternative understanding” (Rossman and Rallis 2017, p. 237).

There are several analytic strategies that qualitative researchers analyze and organize their data. These include content analysis, thematic analysis, discourse analysis, narrative analysis, and semiotic analysis method (Liamputtong 2013; see ► Chaps. 47, “Content Analysis: Using Critical Realism to Extend Its Utility,” ► 48, “Thematic Analysis,” ► 49, “Narrative Analysis,” and ► 50, “Critical Discourse/Discourse Analysis”). Thematic analysis method seems to be the most commonly adopted in qualitative research. It is seen as “a foundational method for

qualitative analysis” (Braun and Clarke 2006, p. 78). Thematic analysis is “a method for identifying, analysing and reporting patterns (themes) within the data” (Braun and Clarke 2006, p. 79; see also ► Chap. 48, “Thematic Analysis”).

Nowadays, there are some software programs, such as NVivo, ATLAS.ti, and MAXQDA, that can assist qualitative researchers with the analysis. This is referred to as “computer assisted qualitative data analysis” (CAQDAS) (Yin 2016; Serry and Liamputtong 2017; see also ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). However, the software programs do not analyze the data per se; they help to manage the qualitative data more efficiently (Creswell and Poth 2018). The researchers still have to perform “all the analytic thinking” (Yin 2016, p. 188). Another word, “the real analytical work” still “takes place in your head” (Patton 2015, p. 531).

It must be noted that qualitative data analysis is a time-consuming process. However, it is also “creative and fascinating.” Sufficient time needs to be dedicated to data analysis in qualitative research. Taylor et al. (2016) contend that data analysis is the most difficult thing for qualitative researchers to teach or communicate to others. Most novice qualitative researchers tend to “get stuck” when they start to analyze their data. Taylor et al. (2016, p. 168) contend that this is because qualitative analysis “is not fundamentally a mechanical or technical process; it is a process of inductive reasoning, thinking and theorizing.” For most qualitative researchers, their ability to analyze their data arises out of their experience. The best way that researchers can learn more about inductive analysis is to work with “a mentor who helps them learn to see patterns or themes in data by pointing these out” and by reading qualitative papers and studies to see how others have come up with their data. This is my recommendation as well.

5 Conclusion and Future Directions

Qualitative research is now a well-established and important mode of inquiry for the social and health science fields (Marshall and Rossman 2016). However, the field of qualitative research is ever advancing (Hesse-Biber 2017). Gaudet and Robert (2018, p. 2) suggest that “qualitative research is a never-ending journey.” This is because “there are always new phenomena to learn about, new methods to invent and new forms of knowledge to create.” We have witnessed this, and chapters in the *Innovative Research Methods in Health Social Sciences* attest to this.

We have also witnessed that qualitative inquiry is increasingly used as part of a mixed methods research (Hesse-Biber 2017). This is clearly articulated in ► Chaps. 60, “Appraising Mixed Methods Research,” ► 39, “Integrated Methods in Research,” and ► 40, “The Use of Mixed Methods in Research”. Creswell and Poth (2018, p. 47) suggest that qualitative research “keeps good company” with quantitative research. However, it is not “an easy substitute for a ‘statistical’ or quantitative study.”

Most importantly, we are now living in a fractured world, where we have and continue to be confronted with social inequalities and injustices in all corners of the

world (Flick 2014). We need qualitative research that can help us to find better answers that better suit people, particularly those who are marginalized and vulnerable (Mertens 2009; Denzin 2015; Flick 2018). Qualitative inquiry can lead to a positive change in the lives of many people. This is what Denzin (2010, 2015, 2017) has advocated. Denzin (2017, p. 8) puts this clearly when he calls for qualitative research that “matters in the lives of those who daily experience social injustice.” We have witnessed critical qualitative research in the last decades or so, and this is also reflected in several chapters in this handbook (see ► Chaps. 12, “Feminism and Healthcare: Toward a Feminist Pragmatist Model of Healthcare Provision,” ► 15, “Indigenist and Decolonizing Research Methodology,” and ► 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology”). I contend that critical qualitative research will continue to play a crucial role in qualitative inquiry in the years to come.

I would like to end this chapter with the Chinese proverb: “The journey is the reward.” The proverb indeed, as Maschi and Youdin (2012, p. 206) contend, underscores “the importance of the process of using a qualitative approach to understanding human experience.” I hope readers who adopt qualitative inquiry will “find it exhilarating and deeply moving.” And indeed, it “can change your worldview” (Rossman and Rallis 2017, p. 10).

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Quantitative Research

3

Leigh A. Wilson

Contents

1	Introduction	29
2	What Is Quantitative Research?	29
3	Describing Data	31
3.1	The Mean	31
3.2	The Median	31
3.3	The Mode	32
3.4	The Range	32
3.5	Percentiles, Deciles, and Quartiles	32
3.6	Variance	32
3.7	Standard Deviation	32
3.8	Prevalence	33
3.9	Incidence	33
4	Probability	33
4.1	The Addition Rule	33
4.2	The Multiplication Rule	34
5	The Normal Distribution	34
6	The Skewed Distribution	34
7	Sampling	35
7.1	Representative Sampling	35
7.2	Sample Size and Statistical Power	36
8	Developing a Research Hypothesis	36
8.1	The Null Hypothesis	36
8.2	The Alternative Hypothesis	37
9	Study Designs	37
9.1	Experimental Study Designs	37
9.2	Nonexperimental (Observational) Study Designs	37
10	Levels of Evidence	38

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10.1	Systematic Reviews	38
10.2	The Randomized Controlled Trial (RCT)	38
10.3	The Cohort Study	39
10.4	The Cross-Sectional Study	39
10.5	The Case-Control Study	40
10.6	The Case Series	40
10.7	Expert Opinion and Reports	40
11	The Placebo Effect	40
12	Bias in Quantitative Research	41
12.1	Selection Bias	41
12.2	Measurement Bias	41
12.3	Researcher Bias	41
12.4	Publication Bias	42
13	Collecting and Handling Data	42
13.1	Categorical Data	42
13.2	Numerical Data	42
14	Types of Variables	43
14.1	The Independent Variable	43
14.2	The Dependent Variable	43
14.3	The Extraneous Variable	43
14.4	The Confounding Variable	44
14.5	The Demographic Variable	44
14.6	The Environmental Variable	44
15	Hypothesis Testing	44
15.1	The <i>P</i> -Value	44
15.2	The Confidence Interval (CI)	45
16	Analyzing Data	45
16.1	Descriptive Data Analysis	45
16.2	Analyzing Categorical Data	46
16.3	Correlation	47
17	Interpreting Quantitative Research	47
18	Conclusion and Future Directions	49
	References	49

Abstract

Quantitative research methods are concerned with the planning, design, and implementation of strategies to collect and analyze data. Descartes, the seventeenth-century philosopher, suggested that *how* the results are achieved is often more important than the results themselves, as the journey taken along the research path is a journey of discovery. High-quality quantitative research is characterized by the attention given to the methods and the reliability of the tools used to collect the data. The ability to critique research in a systematic way is an essential component of a health professional's role in order to deliver high quality, evidence-based healthcare. This chapter is intended to provide a simple overview of the way new researchers and health practitioners can understand and employ quantitative methods. The chapter offers practical, realistic guidance in a learner-friendly way and uses a logical sequence to understand the process of hypothesis

development, study design, data collection and handling, and finally data analysis and interpretation.

Keywords

Quantitative · Research · Epidemiology · Data analysis · Methodology · Interpretation

1 Introduction

Many health professionals consider the conduct of research beyond the realms of their capabilities and, therefore, leave quantitative research to those who are experienced in the field. Others focus on the rich narrative data provided by qualitative research rather than focus on numbers. Quantitative and qualitative research methods are complementary in that they each provide unique and specific information on which to inform and/or develop new clinical or professional practice, change policy, or merely add to the body of academic literature in a given topic area (see also ► [Chaps. 2, “Qualitative Inquiry,”](#) and ► [4, “The Nature of Mixed Methods Research”](#)).

Many healthcare professionals do not wish to undertake research. However, health decisions are increasingly based on the best available evidence, and, therefore, health professionals need to know how to read and interpret the best available evidence published in their field (Liamputtong 2017). This chapter is intended to take the anxiety out of conducting and/or interpreting quantitative methods and to provide a simple overview of the way new researchers and practitioners can understand and employ quantitative research. The chapter offers practical, realistic guidance in a learner-friendly way and uses a logical sequence to understand the process of hypothesis development, study design, data collection and handling, and finally data analysis and interpretation. This is not a chapter designed to give researchers a detailed lesson in statistical analysis or sophisticated techniques; these are best left to experienced statisticians.

Research is fun – it is merely detective work! It is about investigating something that is not fully understood, collecting all the evidence, reviewing the information, and coming up with an explanation. If more people thought this way, research would be far more popular!

2 What Is Quantitative Research?

Quantitative research focuses on the objective measurement of data that are collected through questionnaires, surveys, clinical measurement, or polls and that are analyzed numerically using statistical techniques. The value of quantitative research is that results gained from numerical data in a sample population can be

used to generalize or explain a particular phenomenon in the general population (Babbie 2016).

Quantitative research can be either experimental or descriptive (nonexperimental, i.e., describes a population in specific terms). Experimental research is used to identify whether there is any relationship between two things (called variables) and, if so, whether that relationship is positive or negative. For example, it is known that the greater the amount of exercise one does in a given day is positively associated with levels of fitness (i.e., the more exercise you do the fitter you get) (types of variables will be discussed later in this chapter).

Researchers who use experimental methods seek to identify and isolate specific variables that sit within the framework of the study. Once these are identified, the researchers review the data to determine whether there is any correlation or relationship between the variables or whether there may be a likelihood of causality between variables (i.e., one variable could cause the other). It is critical that researchers attempt to control the environment in which the study is conducted to avoid the risk of variables other than those under study accounting for any relationship identified (McNabb 2007; Babbie 2016; see also ► Chaps. 34, “Single-Case Designs,” ► 36, “Eliciting Preferences from Choices: Discrete Choice Experiments,” and ► 37, “Randomized Controlled Trials”).

There are a number of strengths and benefits of using quantitative research methods. They include:

- An objective viewpoint – thereby minimizing bias and distancing the researcher from the participants of the study
- Greater accuracy of results – gained by employing pre-established statistical techniques
- Larger study sizes with greater generalizability across populations
- The ability to compare data over long time periods to assess changes over time
- The ability to replicate research and compare between studies or similar populations

In order to provide robust and accurate results, researchers assume that quantitative methods are employed consistently and objectively. The results will provide a series of facts (as results), and, while these may be meaningful in statistical terms, they may not be of clinical use or application.

However, there are some limitations to quantitative research which need to be considered:

- Quantitative data may not provide enough context to explain results (unlike qualitative research) (see ► Chap. 2, “Qualitative Inquiry”).
- The use of standardized questionnaires and surveys developed by researchers may lead to bias and reflect the researchers’ ideas or beliefs (see ► Chaps. 32, “Traditional Survey and Questionnaire Platforms,” and ► 76, “Web-Based Survey Methodology”).
- The results may not provide behavioral aspects of research, such as opinions, motivation, attitudes, or feelings (unlike qualitative research).

- Preset answers (such as are contained in surveys) may not be reflective of actual results but are the closest response.

3 Describing Data

In order to get a “feel” for the data under investigation, it needs to be summarized in a meaningful way. Diagrams are a useful way of presenting data visually so that the location and distribution (or spread) of the data can be evaluated. There are standard terms to describe the location and distribution of data within a dataset. The most frequently used are mean, median, mode, range, variance, and standard deviation (see also ► [Chap. 54, “Data Analysis in Quantitative Research”](#)). Within population data, terms such as incidence and prevalence are also used (see also ► [Chap. 33, “Epidemiology”](#)).

3.1 The Mean

The mean (or average) of a set of values is calculated by adding up all the values and dividing the total by the number of values in the dataset. In formulaic terms this calculation is:

$$x^1 + x^2 + x^3 \dots / n$$

where

x = each individual value and

n = the number of values

3.2 The Median

To calculate the median value of a dataset, the data is arranged in order of magnitude, starting with the smallest value and ending with the largest value. The median value is the middle value of the ordered set. Where there is an odd number of values in a dataset, the middle value is the median. However, where there is an even number of values, the two middle values are added together and divided by 2 to obtain the median. The formula for this is:

$$(n + 1)/2$$

where

n = the number of values

3.3 The Mode

The mode is the value in the dataset that occurs most frequently. Some datasets may not have a mode if the values occur only once. Similarly, a dataset can have multiple modes if there is the same frequency of differing values.

3.4 The Range

The range of a dataset is the difference between the largest and the smallest value. These two values are often represented in parentheses rather than the difference between them (x to y). If the dataset contains a number of outliers (data at extreme ends of the dataset), the range is not a good measure of spread. In this situation, percentiles are used to calculate the range.

3.5 Percentiles, Deciles, and Quartiles

Ordering the data from the smallest to largest value will enable percentiles to be calculated. The value of x that has 1% of the observations lying below it is the first percentile. The value with 2% of the values lying below it is the second percentile and so on. The value that has 10% of the values lying below it is the first decile. The values that divide the dataset into four equally sized groups are called quartiles (25%, 50%, 75%). The 50th percentile is the mean.

The interquartile range is the difference between the first and the third quartiles. This range contains the central 50% of the observations in the dataset with each 25% above and below this limit.

3.6 Variance

Another method of determining the spread of the data is to measure the variance or the extent to which each observation (value) deviates from the mean. The larger the deviation from the mean, the greater the variability of the observations. It is not possible, however, to use the mean of these deviations as a measure of spread as the positive differences cancel out the negative differences. To overcome this, each deviation is squared with the mean of the squared deviation described as the variance.

3.7 Standard Deviation

The standard deviation is the square root of the variance. The standard deviation can be considered an “average” of the deviations of the observations from the mean. Dividing the standard deviation by the mean and expressing this as a percentage

gives the coefficient of variation. This is a measure of spread that is independent of the units of measurement.

3.8 Prevalence

The prevalence (commonality) of a disease or given health indicator within a given population is useful in identifying the current health status of a population. Prevalence can be calculated as follows:

Prevalence

= the number of people in a population with a given health indicator during a given time period divided by the population in the same time period $\times 100$.

3.9 Incidence

Incidence can be described as the number of new cases of a given disease or health indicator that occurs over a given time period in a given population. It can be calculated as follows:

Incidence

= the total number of new cases of a given health indicator that occur over a given time period divided by the number of the population at risk during the same time period.

4 Probability

Probability measures the chance that a particular event will occur. A probability value is a positive number that lies between zero and one. If the probability of an event is zero, then the event cannot occur; however, if the probability is one, the event will occur. The rules of probability are the addition rule and the multiplication rule.

4.1 The Addition Rule

If the probability of two events X and Y are mutually exclusive (i.e., each event precludes the other), then the probability of either X or Y occurring is equal to the sum of their probabilities. This can be described as:

$$\text{Probability } (X \text{ or } Y) = \text{Probability } (X) + \text{Probability } (Y)$$

4.2 The Multiplication Rule

If the probability of two events is completely independent from each other, the probability of both events will occur is equal to the product of the probability of each event occurring.

$$\text{Probability } (X \text{ and } Y) = \text{Probability of } (X) \times \text{Probability } (Y)$$

5 The Normal Distribution

In any given population, it can be assumed that the population is normally distributed. That is, there are some population values that lie at the lower end of a curve, with similar numbers of values at the higher end of the curve and the majority somewhere in the middle. This is called the normal distribution, the “bell-shaped curve,” or the Gaussian curve (Wilson and Black 2013) (see Fig. 1).

The normal distribution has a number of distinct features:

- It is symmetrical about its mean.
- It can be described by two parameters: the mean (μ) and the variance (σ^2).
- It is bell shaped.
- It becomes flatter as the variance increases.

The normal distribution has the probability that 68% of the values in a normally distributed dataset will lie within one standard deviation of the mean, 95% within two standard deviations, and 99.7% within three standard deviations of the mean (see Fig. 2).

6 The Skewed Distribution

Skew is a measure of the asymmetry of the probability distribution of a real-valued random variable about its mean. Not all data is normally distributed and may be skewed either negatively or positively. The position of the “tail” in skewed data is the way the skew is described (see Fig. 3).

Fig. 1 The normal distribution (Gaussian curve)

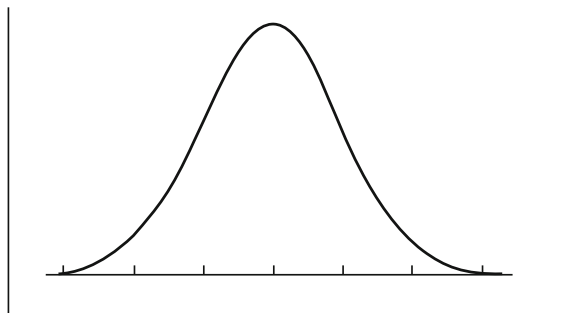


Fig. 2 Percentages of probability under the normal distribution

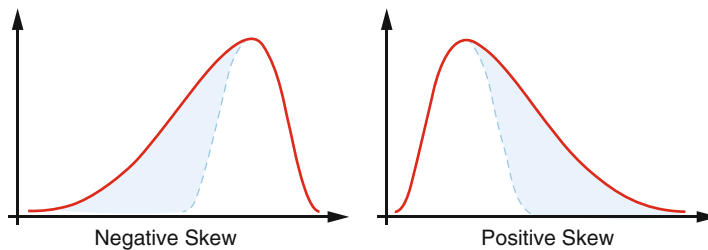
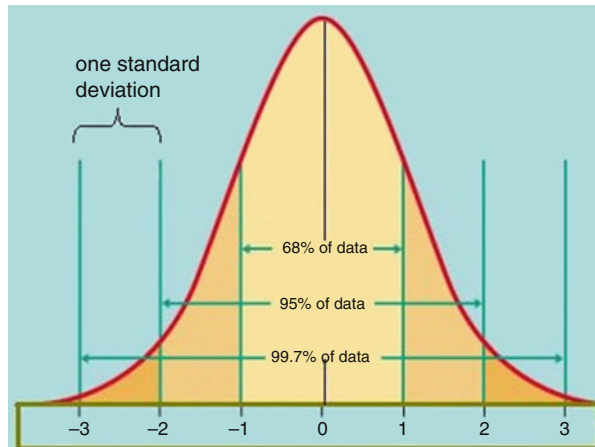


Fig. 3 Negatively and positively skewed distributions

7 Sampling

Because it is costly, time consuming, and impractical to collect data on an entire population of interest, a sample of the population is used. Samples need to be representative of the population of interest so researchers can make inferences about the wider population. Population samples may not fully reflect the normal population, and if this occurs, a researcher is said to have introduced sampling error. There are ways of choosing a population sample that minimize the likelihood of sampling error.

7.1 Representative Sampling

Representative sampling is important so that results are accurate and generalizable to the wider population (see also ► [Chap. 54, “Data Analysis in Quantitative Research”](#)). The best way to ensure sampling is representative is to take a random sample of the population. To do this, all people in the data frame of interest are listed and a sample is chosen at random. In this way, everyone in the data frame has an

equal chance of inclusion in the study. Where this is cost prohibitive or impossible, convenience sampling (i.e., choosing a sample that is convenient to the researcher but still representative) may be used. Other nonrandom methods are sometimes used; however, it is critical to remember that the sample should be as representative of the entire population of interest as possible.

Because a sample population is a subset of the normal population, a normally distributed sample population curve will be flatter than that of a normal population (see Fig. 4).

7.2 Sample Size and Statistical Power

When sample populations are recruited, it is important to ensure the sample is large enough to detect any effect of an intervention. The larger the study, the more statistical power the study has. If the statistical power is high, the chances of accepting the null hypothesis when in fact the null hypothesis is incorrect (there actually is an effect) are less. Power calculations are best conducted by statisticians who can determine the optimal sample size to detect an effect without oversampling which can be costly and time consuming.

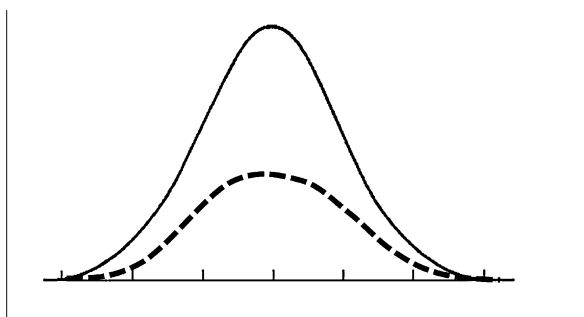
8 Developing a Research Hypothesis

Quantitative research is used when a researcher seeks to answer a specific research question or has a problem (hypothesis) that they want to investigate (or test). Hypothesis testing (sometimes called significance testing) in quantitative research is conducted on either the “null” or the “alternative” hypothesis.

8.1 The Null Hypothesis

The null hypothesis is a statement that assumes the problem being investigated is absent or has no effect (i.e., the difference between means equals zero). For example,

Fig. 4 Population distribution (solid) compared to sample distribution (dotted)



if a researcher were interested in comparing smoking rates between men and women in the population, the null hypothesis (H_0) would be:

H_0 : There is no difference in smoking rates between men and women in the population.

8.2 The Alternative Hypothesis

The alternative hypothesis is defined when the null hypothesis is not true. The alternative hypothesis relates more closely with researcher's beliefs about the research and is expressed as H_1 . Using the previous example, the alternative hypothesis would be:

H_1 : Smoking rates are different between men and women in the population.

9 Study Designs

Once a researcher has developed a hypothesis or a research question, the appropriate study design for that question needs to be chosen. Study designs are chosen by researchers based on the hypothesis and the type of intervention or group under study and are guided by ethical considerations (see ► [Chap. 106, "Ethics and Research with Indigenous Peoples"](#)). Study designs can be classified as either nonexperimental designs or experimental designs (see also ► [Chap. 33, "Epidemiology"](#)). These study designs provide varying levels of evidence. It is not always possible to conduct a study that provides high-level evidence for ethical or logistical reasons.

9.1 Experimental Study Designs

Experimental studies are those where the researcher determines the exposure (or conducts an experiment).

- The randomized controlled trial (RCT) (see ► [Chap. 37, "Randomized Controlled Trials"](#)).

9.2 Nonexperimental (Observational) Study Designs

Nonexperimental studies (sometimes called observational studies) are those where the exposure to a particular event or condition is predetermined. Studies in this category are:

- Cohort studies
- Case-control studies

- Cross-sectional studies
- Other study types (case studies, ecologic studies, case series studies)

10 Levels of Evidence

The evidence (or result) that research provides is based on the strength of the study design. The evidence pyramid visually depicts the strength of evidence for differing study designs (see Fig. 5).

10.1 Systematic Reviews

The highest level of evidence is systematic reviews and meta-analyses. Systematic reviews are research papers which have reviewed a number of high-quality studies on a given topic and consolidated (or pooled) the evidence. Where data from a number of studies has been pooled and reanalyzed (meta-analyses), the resulting data provides much stronger evidence than a single study alone (see ► [Chap. 46, “Conducting a Systematic Review: A Practical Guide”](#)).

10.2 The Randomized Controlled Trial (RCT)

The randomized controlled study is the next highest level of study design. In a randomized controlled trial, a sample of the population of interest is chosen. Each should have similar characteristics to ensure they are representative of the wider population. Subjects are then randomly allocated to either the “intervention” group



Fig. 5 Evidence pyramid for quantitative research

or the “control” group. Data on a range of factors are collected prior to the study commencement and then at the end of the study. Results are then analyzed to determine whether there is any change between these measurements and whether there is any relationship to the intervention. Generally, researchers and participants are “blinded” to the intervention. This is known as a “double blind” RCT. Where either the researcher or the participant are not blinded to the intervention, this is known as a “single blind” RCT. Blinding minimizes bias as subjects cannot choose the group they are in, and it also minimizes the placebo effect (discussed further in this chapter). The RCT is the “gold standard” in study design; however in some cases, the RCT cannot be conducted for ethical or logistical reasons (Wilson and Black 2013; see also ► [Chap. 37, “Randomized Controlled Trials”](#)).

10.3 The Cohort Study

Cohort studies are usually large studies conducted over a long period of time. Researchers follow the cohort of participants in the study and observe the differences between those who have been exposed to a particular phenomenon and those who were not exposed. A good example of a cohort study is the British Doctors Study (Doll and Hill 1954). In this study, doctors were followed over 20 years, and the health of those who smoked was compared to those who did not. This was one of the earliest studies linking smoking to cancer. In a cohort study, all participants must be healthy at the commencement of the study and not have the outcome of interest. Prospective cohort studies follow people over time; however, retrospective cohort studies can also be conducted. In these studies, data collected retrospectively (previously) can be reviewed to ascertain exposure to a particular phenomenon. Databases and medical records are often used to collect retrospective data. There are both strengths and limitations to cohort studies. The strengths are that they provide an unbiased assessment of exposure in a large group of people, it is easy to establish incidence of disease, and rare exposures can be studied. However, cohort studies are expensive and time consuming to conduct and because of their longevity may be prone to bias as researchers change over time or may even lose their relevance by the time the data collection provides results.

10.4 The Cross-Sectional Study

Cross-sectional studies measure exposure and outcome at the same time. They are generally a “snapshot” of a given population at a given time. Cross-sectional studies are especially useful for determining prevalence of a disease within a community and are useful in that they can be conducted relatively, quickly, easily, and cheaply. They are also able to provide prevalence estimates, and they can inform the development of a larger cohort study. Cross-sectional studies are not useful for examining rare conditions and may be prone to bias as they may not be totally representative of the broader population.

10.5 The Case-Control Study

Case-control studies are used to study rare diseases or conditions. They are generally retrospective and start with a “case” who is then matched retrospectively to a “control” (someone without the condition). Differences in exposure to particular factors are then assessed to try and ascertain whether what is observed is different to that expected. Case-control studies are often used in cancer studies to examine exposure to particular substances or conditions. Case-control studies are retrospective and cases are selected based on disease. There are methodological challenges with case-control studies. There is often bias in the selection of cases and controls, it is difficult to match controls to cases, and there may be information bias in what is reported by participants (see ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)). However, case-control studies are often quick, require a smaller sample size, are relatively inexpensive to conduct, and are useful in diseases that are rare or have long latency periods.

10.6 The Case Series

This is a series of cases that are unusual or novel. They may appear in a cluster or over a short period of time. Cases may be highly relevant and in some circumstances are the best evidence available. The cases may or may not be related in time and space, such as an infectious disease outbreak. Case-series studies are not generalizable to the wider population due to their small size; however, they may highlight a particular phenomenon or emerging new disease.

10.7 Expert Opinion and Reports

Expert opinion and editorials are the lowest form of evidence on the evidence hierarchy. This is because opinion is only one person’s perspective and may be heavily influenced by personal values, beliefs, or attitudes rather than quantitative evidence.

11 The Placebo Effect

The placebo effect is defined as “a perceived improvement or change in condition that is due to a psychological response rather than to any active intervention” (Wilson and Black [2013](#), p. 142). A placebo is any medical treatment that is inert (inactive), such as a sugar pill or “sham treatment.” Around one third of people who take placebos (believing them to be medication) will experience an end to their symptoms. This is called the placebo effect.

Because the chance of any intervention having a placebo effect is equal across the population, the likelihood of the placebo effect occurring in either intervention or control groups is also equal. Thus, the chance of bias from the placebo effect is

minimized in RCTs as each group is equally at risk of developing the placebo effect (see ► [Chap. 37, “Randomized Controlled Trials”](#)).

12 Bias in Quantitative Research

Bias is defined as any influence that prejudices an outcome. The Webster dictionary defines research bias as that when “systematic error [is] introduced into sampling or testing by selecting or encouraging one outcome or answer over others” (Merriam-Webster.com 2017). Researchers often have a “hunch” about what they are likely to find in their research; however, it is critical that the influence of the researcher is eliminated from the research study; otherwise biased results will eventuate.

Bias can occur at any phase of research, including study design or data collection, as well as in the process of data analysis and publication. The most common types of bias are measurement bias, selection bias, researcher bias, and publication bias (see ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)).

12.1 Selection Bias

According to Panucci and Wilkins (2010, p. 3), “selection bias may occur during identification of the study population.” In order to ensure a suitable study population, the sample should be clearly defined, accessible, reliable, and at increased risk to develop the outcome of interest. Selection bias occurs when the criteria used to recruit and enrol patients are inherently different (Portney and Watkins 2009). This can be a particular problem with case-control and retrospective cohort studies where exposure and outcome have already occurred at the time individuals are selected for study inclusion (Pannucci and Wilkins 2010).

12.2 Measurement Bias

Measurement bias occurs when there is a systematic error in the way data is measured. This may include an incorrectly calibrated instrument, incorrect measurement tools, recall inconsistencies (sometimes called recall bias), or incorrect measurement between two researchers.

12.3 Researcher Bias

This can occur when a researcher selectively “chooses” particular patients to be included in a study because they suspect they will benefit from the intervention. Although the researcher may be blinded as to the group in which the patient is included, the researcher may treat the patient differently to others or make comments to the patient that may influence the way any intervention or control medication works.

12.4 Publication Bias

Publication bias may occur when researchers and/or funding organizations are unwilling to publish negative research results, because they believe that this may impact on their reputation or credibility. As a result, positive results are more likely to be submitted for publication than negative results.

13 Collecting and Handling Data

The purpose of all quantitative research is to collect data to obtain information about a particular topic or given area of research. Data are observations or measurement of a particular variable. Variables are characteristics of interest in a given population. For example, researchers may collect data on the following variables: age, sex, height, weight, and smoking status. Variables can be classified into either categorical (qualitative) data or numerical (quantitative) data.

13.1 Categorical Data

Categorical data are those which can be put into categories as the data are not numerical. Categorical data can be further classified as nominal, ordinal, or dichotomous.

13.1.1 Nominal Data

Nominal data are data in categories that have names. Examples include eye color (blue, green, brown, gray), blood group (A, B, AB, O), and marital status (married, widowed, single, divorced).

13.1.2 Ordinal Data

Ordinal data are data in categories that are ordered in some way. The data may be ordered on a “scale” series of levels, for example, pain scores (none, mild, severe, extreme) or disease progression (Stage 1, Stage 2, Stage 3, Stage 4).

13.1.3 Dichotomous Data

Dichotomous data (sometimes called binary data) has only two categorical options. This may include Yes/No, Diseased/Non-diseased, Dead/Alive, and Male/Female.

13.2 Numerical Data

Numerical data occur when the variable has a numerical value. These can be divided into two types: discrete data and continuous data.

13.2.1 Discrete Data

Discrete data are those where the variable can only take certain numerical values. Examples include number of GP visits in 1 year, number of falls in the last month, or number of episodes of asthma in 12 months.

13.2.2 Continuous Data

Continuous data are those that have an infinite number of values. Examples are blood pressure, height, weight, and length.

14 Types of Variables

Experiments cannot exist without variables as these are the data points that are held constant or manipulated in an experiment. A variable is a characteristic that can be varied or changed, for example, height or weight. There are six types of variables which are usually identified in experiments: dependent, independent, extraneous, confounding, demographic, and environmental. Each type of variable should be clearly defined at the commencement of a study, with the last four variables discussed as limitations of the study.

14.1 The Independent Variable

The independent variable is the cause of the outcome. It is manipulated so it is independent of any effect. The independent variable is always the intervention that is applied (Wilson and Black 2013).

14.2 The Dependent Variable

The dependent variable is the effect or the consequence of the independent variable, so it depends on it for any change to occur. It is observed and measured and, therefore, must have the ability to vary or change. Multiple independent and dependent variables can be used in a study, and they should be explicitly stated.

14.3 The Extraneous Variable

Extraneous variables have the potential to impact upon the reliability of a study. It is possible to control for extraneous variables at the commencement of a study by considering what external factors may impact upon the outcome of interest. For example, if researchers were measuring temperature in a sample of participants but half of them were sitting next to a hot radiator, this would

impact upon results. The extraneous variable would be “location when temperature was taken.”

14.4 The Confounding Variable

Confounding variables are those that occur outside the study framework but that can impact upon the reliability of the results. Unlike extraneous variables, it is impossible to control for confounding variables. Such factors include the weather, genetic disposition, past experiences, and age.

14.5 The Demographic Variable

Demographic variables are those that are collected to describe the characteristics of the sample. These include such characteristics as age gender, height, weight, socioeconomic status, work history, education level, and so on. Depending on the study hypothesis and design, the demographic variables may be constrained (e.g., only females) or very diverse.

14.6 The Environmental Variable

Environmental variables are similar to extraneous variables, in that they can be controlled for in a laboratory. These variables include characteristics such as temperature, light, wind speed, humidity, and so on.

15 Hypothesis Testing

Quantitative researchers gather data in order to test a hypothesis. This enables the researcher to quantify a belief against a particular hypothesis. After collecting the data, the resulting values can then be used in a formula to undertake a specific test and obtain a test statistic. The test statistic will provide the amount of evidence against the null hypothesis. Common test statistics include the P -value, confidence intervals (CI), z statistic and χ^2 statistic, and t -value (see also ► [Chap. 54, “Data Analysis in Quantitative Research”](#)).

15.1 The P -Value

All test statistics follow known theoretical probability distributions. The test statistic from the sample is then related to the known population distribution to determine the P -value (the area in both (sometimes one) tails of the distribution. The P -value is the probability of obtaining these results or something more extreme, if the null hypothesis is true. Put another way, the P -value is the likelihood that the result we have obtained

occurred by chance. The smaller the P -value, the less likely the result occurred by chance. Generally, researchers are satisfied that if the P -value is less than 0.05 there is a statistically significant result. This is described as being significant at the 5% level.

The choice of 5% is an arbitrary figure and means that on 5% of occasions we may reject the null hypothesis when it is true. Where this has a high level of clinical significance, researchers often use 0.01 or 0.001 as the chosen cutoff for the P -value so that the chance of error is less.

15.2 The Confidence Interval (CI)

According to Petrie and Sabin (2005, p. 28), “the confidence interval quantifies the difference in means and enables researchers to interpret the clinical implications of the results.” Because the CI provides a range of values for the true effect, it can be used to make a decision, even in the absence of a P -value.

16 Analyzing Data

Most data analysis is now done using sophisticated computer programs that can calculate test statistics and perform complex data analysis in the blink of an eye. The following section is not written to enable the reader to calculate statistics; this is best undertaken by statisticians that have studied the theories of statistical analysis for years. It is written to assist the reader to understand what types of tests are used and to familiarize them with the terminology related to statistical analysis.

16.1 Descriptive Data Analysis

Demographic variables and descriptive data can be presented using mean, median, range, and percentages to outline the characteristics of the sample population.

16.1.1 Continuous, Ordinal, and Numeric Normally Distributed Data

The One Sample T-Test

Researchers generally assume (if all care has been taken with sampling) that the sample population is normally distributed with a given (usually unknown) variance. Where there is one sample dataset to be analyzed, researchers use a one sample t -test to compare the sample to the normal distribution. This will give a P -value and confidence intervals.

The Paired T-Test

Where there are two samples who are related to each other (such as in a case-control study or where data are being measured on the same participants over two occasions), a paired t -test is used. Normal distribution is assumed, and because of the

paired nature of the data, the samples must be of the same size. Applying the *t*-test will identify any differences in the means between the two populations. The test statistic (*t*) is compared to values from a known population distribution. This will then give the *P*-value so the CI can be calculated.

The Unpaired T-Test

Where the sample sizes are large (i.e., have enough power), it can be assumed that the data are normally distributed. In two unrelated groups (such as an intervention group and a control group), an ordinal or numerical variable can be investigated to determine whether the means or distribution of the groups is the same. Assuming the data is normally distributed, the null hypothesis suggests that the difference between the means will be zero (that is, an intervention will have no effect). Where there is a difference in the means, the *t*-statistic will be greater than 1.96 (at the 5% level). Where this is the case, the researchers can reject the null hypothesis and report the *P*-value as statistically significant (i.e., the likelihood that the result occurred by chance is less than <5%). Assuming variances in the groups are equal, CIs can be calculated for the difference in the two means.

Analysis of Variance (ANOVA)

Where there are more than two groups in a sample dataset, the statistical test applied is known as an “analysis of variance” (ANOVA). This test is a more complex statistical analysis that compares the “between group” variation and the “within group” variation. The components of variation are measured using variances (hence the term ANOVA). Based on the null hypothesis that the group means are the same, the between group variance will be similar to the within group variance. However, if there are differences between groups, then the between group variance will be larger than the within group variance. The test is based on the ratio of these variances.

16.1.2 Continuous, Ordinal, and Numeric Non-normally Distributed Data

Where continuous, ordinal, or numeric data is not normally distributed, there are a number of ways to analyze the data, either nonparametric tests are used to investigate the data depending on the sample (single, paired, or unpaired) or the data can be log transformed. Log transformation is a process whereby a formula is applied to the data to make the distribution more normal.

16.2 Analyzing Categorical Data

Analytical methods on categorical data are different to continuous and ordinal data. The test statistics used are the χ^2 (Chi-square statistic), *z* statistic. These test statistics give us the final *P*-value and CI for the sample.

16.2.1 The Test of a Single Proportion

Where there is a single sample with a given number of participants, each participant either possesses a characteristic of interest (male, pregnant, alive) or does not possess those characteristics (female, not pregnant or dead). It is useful to determine how many individuals in the sample display the characteristic, and this is defined as the proportion.

16.2.2 The Test of Two Proportions

A test of two proportions can be conducted when there are two independent groups of individuals or when there are two related groups. Investigating the proportion of individuals in a group with a particular characteristic may identify whether there is any significant difference between one group and the other. In related samples (the same group measured twice or where individuals are matched), the differences between results can be measured using proportions. In this situation, a Chi-square (χ^2) test is applied to the data. This will provide a test statistic which can be compared to a normal distribution to get a *P*-value, and the confidence interval can then be determined.

16.2.3 The Test of Three or More Proportions

Where there are three or more proportions (e.g., blood group A, B, AB, or O), we can investigate the frequencies of each category. The expected frequency and the observed frequency are calculated and the χ^2 test is applied. The test statistic that results focuses on the discrepancy between the observed and expected frequency of each result. The test statistic can then be compared to a normal distribution to give a *P*-value.

16.3 Correlation

Correlational analysis is concerned with measuring the relationship between two numerical variables (x and y). These variables can be plotted on a scatter graph with the values for x on the horizontal axis and the values for y on the vertical axis. The resulting scatter of points may indicate a relationship between the variables (see Fig. 6). Where there is a linear relationship between variables (a line can be drawn in a particular direction – either positive or negative), a correlation between the variables exists. The correlation coefficient describes the strength of the correlation and is always between zero and 1 or zero and -1. A strong positive correlation would approximate 1, and a strong negative association would approximate -1. A dataset with no correlation has a correlation coefficient of zero.

17 Interpreting Quantitative Research

Health professionals are bombarded with new research information everyday. It is estimated that around 2.5 million peer-reviewed papers are published each year (Olesen Larsen and von Ins 2010). One of the most difficult aspects for health

SCATTERPLOTS & CORRELATION

Correlation - indicates a relationship (connection) between two sets of data.

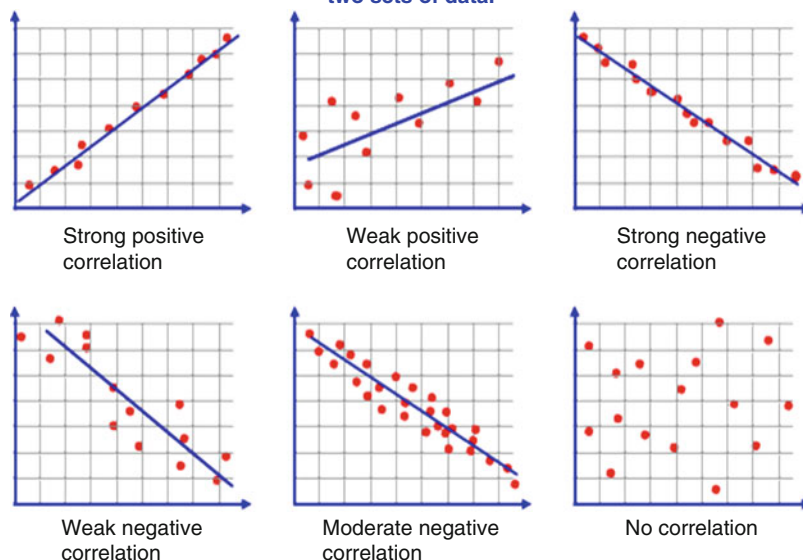


Fig. 6 Scatterplots and correlation

professionals is the ability to interpret research articles and to distinguish “high” quality research from “poor” quality research. The majority of journals that publish medical and health research have a peer review process that is thorough and robust. The peer review process includes a detailed review by experts in the field, who will assess the methods used, sample size, and limitations of the study. A study may be rejected for publication if it does not meet the rigorous standards of the journal or is deemed to be poorly conducted (see also ► [Chap. 59, “Critical Appraisal of Quantitative Research”](#)).

Interpreting results published in journals is best undertaken by thoroughly investigating the methods used by the researchers. Health professionals should question whether the methods used are appropriate for the type of study (study design) and whether the statistical analysis is thorough and robust (was the right test used for the type of data collected). Interpreting *P*-values and confidence intervals enables the reader to determine whether the researchers obtained statistically significant results in a study. On occasion, statistically significant results are not obtained due to limitations of the study (there may not be enough participants, or there was a confounding factor that was not considered). Where this type of study is published, readers are able to determine the methods used by researchers and familiarize themselves with some of the challenges and pitfalls of research.

18 Conclusion and Future Directions

Quantitative research methods are concerned with the planning, design, and implementation of strategies to collect and analyze data (Sheehan 1986). Descartes (1637) suggests that *how* the results that are achieved is often more important than the results themselves, as the journey taken along the research path is a journey of discovery. High-quality quantitative research is characterized by the attention given to the methods and the reliability of the tools used to collect the data. The ability to critique research in a systematic way is an essential component of a health professional's role in order to deliver high quality, evidence-based healthcare. The rise in technology and the ability to easily calculate complex statistics will impact on the type and complexity of data available using quantitative methods. Although these data provide a numerical overview of the population, it is important to remember that quantitative methods are only one way of analyzing data. Triangulation with qualitative methods in mixed methods research provides an in-depth overview of the population.

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The Nature of Mixed Methods Research

4

Cara Meixner and John D. Hathcoat

Contents

1	Introduction	52
1.1	Defining Mixed Methods	52
1.2	The Evolution of Mixed Methods Research	53
1.3	Mixed Methods: A Contemporary Context	54
1.4	Example of MMR in Health Social Sciences	56
2	Philosophical Positions	57
2.1	Frameworks	57
2.2	Paradigmatic Challenges and Successes	59
3	Major Approaches	61
3.1	Convergent Design	63
3.2	Explanatory Sequential Design	63
3.3	Exploratory Sequential Design	64
3.4	Intervention Design	65
3.5	Hybrid Design Choices	66
4	Getting Started	67
5	Conclusion and Future Directions	68
	References	69

Abstract

Mixed methods research (MMR) has gained traction in the social sciences, evolving as a genre of inquiry that intentionally and systematically connects qualitative and quantitative methods in order to address substantive questions.

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Mixed methods projects are often preplanned, resulting in a fixed design. MMR can also be emergent; a researcher may craft a follow-up qualitative study, for instance, to make meaning of elusive quantitative findings. We unveil the nature of mixed methods research in the context of philosophical positions (e.g., constructivism, postpositivism, advocacy, and pragmatism) with critical attention to successes and challenges (e.g., incompatibility, conditional incompatibility, integration). Drawing from examples in the health social sciences, we showcase major mixed methods approaches – such as convergent parallel, exploratory, explanatory, intervention, and hybrid designs – while attending to notions of mixing, timing, and weighting data. Criticisms and accolades regarding MMR are thread throughout the chapter, given their parallels to phases in research design. Pivotaly, the chapter also addresses ways that readers can “get started” on their own mixed methods projects.

Keywords

Mixed methods research · Research design · Philosophical positions · Convergent parallel design · Exploratory design · Explanatory design · Intervention design · Hybrid design · Constructivism · Postpositivism · Advocacy · Pragmatism

1 Introduction

This chapter orients students and novice researchers in the health social sciences to mixed methods research (MMR), a genre of inquiry that intentionally and systematically connects qualitative and quantitative methods in order to address substantive research questions. MMR is particularly well suited to the health social sciences, wherein researchers use social science tools to investigate and make meaning of human health. Inquiry into the topic of health is as deep as it is vast, necessitating a diverse set of methods. To understand the layered experience of caregiving for cancer survivors, for instance, one would employ a fundamentally different set of methodological tools than those we would use to predict the effect of the rural opioid epidemic on income security.

To fathom MMR as a vibrant, integrative approach to health social sciences research, we first turn to its evolution. From there, we will gaze into MMR as it stands currently, with attention given to the contemporary landscape of inquiry in the healthcare field. Parcel to understanding MMR is exploring related philosophical positions, implicit and explicit, that frame methodological work. Then, we orient the reader to major mixed methods designs (i.e., convergent parallel, exploratory, explanatory, and intervention) and their affiliated assumptions. Each of these facets is intended, ultimately, to guide our audience in contemplation of the chapter’s final intent: to invite readers to “get started” on their own MMR endeavors.

1.1 Defining Mixed Methods

Meanings, classifications, and implications of MMR have varied across each of the periods described in the following subsection. Across the disciplines, among the more known definitions arises from Creswell (2015, p. 2), who views MMR as:

An approach to research in the social, behavioral, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems.

Within this chapter, Creswell's definition will be endorsed, with attention given to its implications for the health social sciences. However, we would be remiss not to add the rich, thoughtful conjectures on MMR drawn from Johnson and Onwuegbuzie (2004, p. 17):

Mixed methods research also is an attempt to legitimate the use of multiple approaches in answering research questions... It is an expansive and creative form of research, not a limiting form of research. It is inclusive, pluralistic, and complementary, and it suggests that researchers take an eclectic approach to method selection and the thinking about and conduct of research.

1.2 The Evolution of Mixed Methods Research

From the Latin verb *evolvere*, the term *evolution* points to steady development, from simple to complex, and to a pattern of movements or turns. Both definitions aptly describe the growth of MMR and the various factors – philosophical, sociological, and political, among others – that have influenced its development. While Creswell and Plano Clark (2018) trace MMR's formal beginning to the late 1980s, during which there was a confluence of seminal publications across varying disciplines, credit can be drawn to the early work of Campbell and Fiske (1959). They pioneered a multi-method approach, suggesting the inclusion of multiple quantitative measures to study psychological traits. As the decades turned, researchers like Sieber (1973), Denzin (1978), and Jick (1979) combined quantitative and qualitative methods in an effort to better understand research enigmas and phenomena.

This formative period in the evolution of MMR was interjected by paradigmatic debates (see Rossman and Wilson 1985; Bryman 1988; Reichardt and Rallis 1994; Greene and Caracelli 1997), wherein scholars took varying stances regarding the philosophical legitimacy of mixing qualitative and quantitative data. At the center of the argument was the issue of incompatibility between the overarching paradigms under which qualitative and quantitative inquiry respectively reside. Just because data *can* be mixed to formulate a holistic understanding of a research problem, *should* they be? As the reader might imagine, this historical stage had its drawbacks, particularly in advancing MMR. Johnson and Onwuegbuzie (2004, p. 14) opined:

The quantitative versus qualitative debate has been so divisive that some graduate students who graduate from educational institutions with an aspiration to gain employment in the world of academia or research are left with the impression that they have to pledge allegiance to one research school of thought or the other... A disturbing feature of the paradigm wars has been the relentless focus on the differences between the two orientations.

In spite of the schism between qualitative and quantitative researchers, what emerged during this timeframe, and is explored later in this chapter, is the notion

of understanding and critically interrogating research methods within their broader philosophical assumptions (e.g., ontology, epistemology), mental models (Greene 2007), and associated claims. Though the paradigmatic debates linger, scholars' contributions to issues like transparency (see Greene and Caracelli 1997) and reflexivity have grown increasingly significant.

In the 1980s, attention "began to shift toward the early procedural development period in the history of mixed methods in which writers focused on methods of data collection, data analysis, research designs, and the purposes for conducting a mixed methods study" (Creswell and Plano Clark 2018, p. 27). These developments established ground for the advocacy and expansion of mixed methods, wherein authors such as Johnson and Onwuegbuzie (2004, p. 17) pronounced MMR as "the 'third wave' of the research movement, a movement that moves past the paradigm wars by offering a logical and practical alternative." Further, mixed methods have gained credence within publications, conferences, text and reference books, and funding agencies (e.g., National Science Foundation, National Institutes of Health).

Creswell and Plano Clark (2018) suggested that a reflective and refinement period for MMR commenced in 2003, with two prominent and related features: (1) discussions assessing the MMR field and projecting its future and (2) constructive critiques on the field's emergence and evolution. Therein, the authors cited criticisms from nursing research. For instance, varied voices (e.g., Giddings 2006; Holmes 2006; Freshwater 2007) challenged issues such as the false polarization of quantitative and qualitative methods, a risk on the part of MMR to marginalize qualitative inquiry, and the flat presentation of MMR (i.e., rhetoric, discourse). Scholars also sought clarity on how to *evaluate* mixed methods contributions (Morse and Niehaus 2009), a question that continues to pervade discourse (see ► Chap. 60, "Appraising Mixed Methods Research").

1.3 Mixed Methods: A Contemporary Context

Halcomb, Andrew, and Brannen (2009) connected current trends in nursing and health sciences to a need for vigorous mixed methods studies. Advances and changes in healthcare, rising costs, an aging population, and the complexities related to disease, among other factors, co-create a need to review provider roles and assess the viability of best practices. Of note, Halcomb et al. (2009) purported that MMR is not necessarily a new approach in the health sciences; it has been parcel to many scholars' approaches – often covertly. The authors further stated that:

What are new, are the emerging impetuses that are leading researchers to methodological change and advancement. Where previously people were reluctant to disclose this combination of approaches, researchers are now discussing frank and meaningful information regarding methodological issues leading to innovation and the greater potential to have a repertoire of skills appropriate to a range of research questions. (p. 7)

In consideration of MMR in the health social sciences, Halcomb et al. (2009) invited novice and skilled scholars to consider five points of impetus that drive a continued need for methodological pluralism. These points are summarized in

Table 1. We have added reflection questions to guide the reader's personal consideration of these premises.

Also germane to those reading this chapter is a contemporary context etched in the landscape of funding, which is especially relevant given costs associated with studies of human health. To this end, the Office of Behavioral and Social Sciences Research (OBSSR) of the NIH published *Best Practices for Mixed Methods Research in the Health Sciences* (Creswell et al. 2011). Freely available, the document guides the reader through an abbreviated introduction to MMR, leading into how a researcher might prepare applications for NIH-funded research projects, small grants, and exploratory/developmental research grants. Among the core

Table 1 Impetus for use and range of mixed methods in the health social sciences

Impetus	Meaning	Reader reflection
Increased reflexivity in relationships	Researcher sensitivity and reflection drive not only what is studied but also how and with whom the study takes place	<i>What is my relationship to the phenomena I study? Why is that so? What drives this interest? With whom do I forge research relationships? Where are my beliefs, biases, and values present? Am I transparent about these facets?</i>
Increased political awareness of research	Recognition that research has a political bent, influencing policymaking, practice, and change	<i>For what purposes or goals (micro, meso, and macro), am I engaged in research in the health social sciences? How might my research be interpreted and used by various stakeholders? To what end do the methods I intend to use reflect valued aims of inquiry?</i>
Growing formalization of ethics and governance	Awareness that research into human health must be situated in ethical frameworks that require approval and consent	<i>What are the ethical implications of my purported study? Have I sought all requisite approvals (e.g., human research ethics committees)? In what ways could the methods serve to oppress or liberate participant perspectives?</i>
Availability and ease of technologies	Technologies present ever-changing opportunities for data collection, analysis, and integration	<i>What technologies make it plausible to collect, analyze, compare, and integrate data? How might these technologies also help ensure a diverse array of participants – Or consumers of research, for that matter?</i>
International research collaboration	Globalization makes collaboration possible, but this is also a heightened call from funding bodies	<i>What can we learn through international partnerships into the investigation of human health? How do international partnerships inform the ethical, methodological, and productive features of health social science research?</i>

contributions is an acknowledgment that in writing the innovation section of a research grant, “the use of mixed methods researchers may be an innovation in and of itself” (p. 19). This positions MMR not only as a tool to addressing complicated phenomena but also as a methodology worthy of recognition for its own advance. That the NIH and other prominent foundations and agencies (e.g., NSF) forwardly invite MMR submissions is another indication of the “third wave’s” merits.

1.4 Example of MMR in Health Social Sciences

We offer an example, drawn from the first author’s own research (see Meixner et al. 2013), to provide insight into MMR in the health social sciences. As with many research questions, ours arose from practice and is situated in an advocacy agenda for survivors of brain injury. Our initial inquiry, which focused on obstacles to accessing crisis intervention services in rural loci, surfaced from multiple vantage points. The intersected identities on our research team included that of clinical expert, director of a nonprofit organization serving persons with brain injury, caregiver, and research methodologist. Together, we had observed, over time and firsthand, what appeared to be substantive gulfs in services, particularly when survivors experienced acute crisis. Gaps in the literature further sensitized us to the need for additional inquiry. Our overarching question thus became: What are the barriers to accessing crisis intervention services for persons with brain injuries?

Practically speaking, MMR provided us with the most integrative, comprehensive toolkit to understand a complex question. Yet, our choice to pursue MMR was multifold. One, the canon of literature helped us see a complex connection between psychiatric comorbidities, cognitive and behavioral changes, funding limitations, systemic obstacles, and more. These factors had been explored quantitatively, and often discretely, leaving scholars with unresolved questions. Specifically, the literature precluded an interdependent analysis of barriers, a focus on rural loci, and a research design principled on rigorous mixed methods inquiry. We also knew that qualitative inquiry would invite novel perspectives given the deep, nuanced explorations of social processes that robust narrative and phenomenological methods make possible.

As scholar-practitioners, we also acknowledged that our intentions were action-oriented, with a desire to inform plans to improve intervention and mental health services while building relationships across providers. Relevant to action research is the intent to disrupt the status quo, challenge norms, and transform systems (Argyris et al. 1985; Anderson and Herr 2005). To this end, we noted: “Equally vital in action research is the empirical analysis of diverse perspectives, which can neither be ascertained by quantitative nor qualitative data alone. [MMR arrives]. . . at a more complex understanding of the research question” (Meixner et al. 2013, p. 379). Finally, we surmised our stakeholders (i.e., academics, providers, policymakers, survivors, etc.) would value the juxtaposition of qualitative and quantitative methods. Though the resident literature was dominated by quantitative and quasi- and non-experimental designs, we observed the field of practice to be one that valued the narrative, non-experimental tradition.

The study involved two phases of data collection and analysis; we commenced with a web-based survey, comprised primarily of quantitative questions. Data from

110 participants (49% response rate) were analyzed to inform the development of a second, qualitative strand of inquiry. Herein, we reflected on the tremendous advantage MMR provided – such as the opportunity to utilize qualitative inquiry to explore, identify, and unpack the barriers elicited in the quantitative strand. We conducted seven focus groups ($n = 25$), analyzing the data for resonance and divergence with its quantitative counterpart. A rigorous analysis yielded themes and minor inconsistencies across both strands of inquiry:

A multipart analysis of the focus group data revealed. . .the most critical barriers to accessing services. . . [T]hese obstacles are connected, affecting each other and deepening fragmentation in the system. The nature of these findings as symbiotic adds significant value to the literature, expanding providers' awareness of the layered complexity of brain injury and access to services. Of note, the qualitative phase supported quantitative findings with the exception of [one subtheme]. (p. 383)

In spite of the obvious and surprising benefits of our approach, we were not without obstacles and encumbrances. MMR is labor intensive, requiring scholars both literate and skilled in rigorous statistical and qualitative methodologies. As discussed in the next section, such proficiency is not just methodological; researchers must also attend to paradigmatic assumptions, explicit and covert, governing inquiry. Within our postpositivist neurotrauma research community, for instance, some of our peers discounted the value of the qualitative strand, yet their counterparts in the advocacy community upheld the rich, bountiful perspectives as evidence of a flawed system of care. Not all of the publications we considered were welcoming of MMR so we had to be vigilant in locating venues of mutual advantage. These challenges, while present, did not undermine the vigor of the process we upheld. In all, the MMR approach resulted in a thorough understanding of a complex phenomenon through the collection, analysis, and interpretation of quantitative and qualitative data.

2 Philosophical Positions

Philosophical stances, what some refer to as paradigms, have been a topic of much debate in the MMR literature. This is partly due to the historical evolution of MMR that was previously discussed. Can we integrate quantitative and qualitative data within a single study if they are informed by seemingly contradictory philosophical positions? If not, is the notion of MMR simply nonsensical? To contextualize these issues, we provide an overview of four philosophical stances that are discussed by Creswell (2014). This is followed by an examination of some of the paradigmatic successes and challenges manifest within MMR.

2.1 Frameworks

As professors, we find ourselves engaged in conversations with budding scholars about the intersection between ontology, epistemology, and axiology in social

science research. “What’s *philosophy* got to do with my research project?” inquired one precocious student keen on pursuing a mixed methods thesis. Our answer is, well, “*Everything!*” Whether overt or implicit, scholarly inquiry exists within and around philosophical perspectives – also referred to as paradigms or worldviews. To abscond consideration of philosophy in research methods would be akin to traveling to a new country without having considered its cultural manifestations, like collective rites, language, laws, history, and so on. For individuals new to the concept of philosophical positions, Creswell’s (2014) primer is a useful starting place for understanding their role in research. Though numerous philosophical stances exist, he elaborated on four views: postpositivist, constructivist, transformative, and pragmatist. Each view is laden with assumptions regarding *ontology* (i.e., the nature of knowledge), *epistemology* (i.e., how we come to know something), *axiology* (i.e., the role of values in inquiry), *rhetoric* (i.e., how we write or project our findings), and *methodology* (i.e., the processes we utilize to understand our question) (see also ► Chap. 6, “Ontology and Epistemology”).

Our students tend to find postpositivism the easiest stance to grasp; inclusive of the procedures traditionally adopted within science, this philosophical position contends that there is an independent reality that can, at least approximately, be known (Crotty 1998). In other words, there are objective aspects of human health that researchers aim to discover using rigorous methodological techniques (see also ► Chap. 9, “Positivism and Realism”). Though we may know never know with certainty that our best scientific theories are true, they serve as our closest approximations to an objective reality since they have withheld empirical scrutiny. Generally speaking, the standards of rigor include what is taught in many research methods textbooks (e.g., sampling, reliability, validity, generalizability, and so on). Researchers are, therefore, expected to remain distant from the topic of investigation since they could introduce various forms of bias – as illustrated by the need for researchers to be unaware of whether a participant is in an experimental or control group in randomized control trials (see ► Chap. 37, “Randomized Controlled Trials”).

In contrast to postpositivism, social constructivism assumes that meanings are not only co-constructed but also multiplistic, varied, and highly contextual (see also ► Chap. 7, “Social Constructionism”). Constructivism guides deep inquiry into phenomena that may be impervious to the reductive techniques and standards that dominate the milieu of postpositivism. To compare these two, let us consider the musings of two scientists, Lanza and Berman (2009, p. 4), intent on understanding an ineffable construct:

Consciousness is not just an issue for biologists; it’s a problem for physics. Nothing in modern physics explains how a group of molecules in your brain create consciousness. The beauty of a sunset, the miracle of falling in love, the taste of a delicious meal—these are all mysteries to modern science. Nothing in science can explain how consciousness arose from matter. Our current model simply does not allow for [it].

The essence of consciousness, thus, is fodder for constructivist inquiry and would likely draw from a qualitative method, such as phenomenology, for exploration.

Herein, the role of researcher diverges from that explored above; the scholar is, herself, a tool in the elicitation and construction of meaning.

The third position that Creswell (2014, p. 9) reviews is the transformative worldview, which “arose during the 1980s and 1990s from individuals who felt that the postpositivist assumptions imposed structural laws and theories that did not fit marginalized individuals in our society or issues of power and social justice, discrimination, and oppression that needed to be addressed.” Thus, studies under the umbrella of advocacy – focused on change, emancipation, and/or justice – are often integrated with critical theoretical perspectives (e.g., feminist, queer, disability) and draw from both quantitative and qualitative methods to advance desired aims. Under this approach, researchers are often participant-observers who work with other participants to develop questions, make meaning of results, and evoke changes to promote social justice (see also ► Chap. 17, “Community-Based Participatory Action Research”). An advocacy approach is technically consistent with a range of philosophical stances (Hathcoat and Nicholas 2014; Nicholas and Hathcoat 2014). However, at the center of an advocacy approach resides the recognition that inquiry is inherently value-laden, collaborative, and transformative. Described above, our illustrative study (Meixner et al. 2013) is emblematic of this claim.

The pragmatist knowledge claim, fourth in Creswell’s (2014) heuristic, may abscond commitment to any one ontological or epistemological underpinning, focusing instead on researchers’ freedom “to choose the methods, techniques, and procedures of research that best meet their needs and purposes” (p. 12). Primary importance is given to aligning the question asked with the MMR approach and assuring focus is paid to the *consequences* of research (Creswell and Plano Clark 2018; see also ► Chap. 40, “The Use of Mixed Methods in Research”). Such liberalism leads many mixed methodologists to situate their studies under the auspices of this claim, touting pragmatism as the “what works” approach. This can be problematic, as we believe pragmatism can be as misunderstood as it is haphazardly applied (Hathcoat and Meixner 2017). Bryman (2007) would concur; he found that many MMR scholars cast aside philosophical issues in order to procure funding and publish their results. This issue is further attended to below.

2.2 Paradigmatic Challenges and Successes

Several years ago, we were working with a doctoral student, to whom we will refer as Nadia, whose mixed methods study was dominantly quantitative and supported by a qualitative strand. Well trained in advanced statistical methods, Nadia was likewise aware of her postpositivist inclinations. Still, she held immense respect for qualitative research, recognizing that subjecting her qualitative method, techniques, and data to the “standards” of the postpositivist paradigm would be deleterious. But, this did not assuage her worries about how the data would be integrated and understood. Various questions came to mind: How might Nadia situate her study, philosophically? Why does doing so matter, to begin with? Is the study pragmatist in philosophical orientation? Or, should Nadia consider a shift among paradigms,

allowing postpositivism to guide the quantitative phase, with constructivism orienting the qualitative phase? Further, what are the repercussions of conjoining paradigms, and their methods, in the interpretation process?

These are the very puzzles that continue to vex mixed methods scholars. As we touched on above, issues of incompatibility emerged in the 1960s and 1970s, a time during which qualitative research became more widely advanced in the social sciences (Hanson et al. 2005). The incompatibility thesis states that quantitative and qualitative research, informed by opposing philosophical assumptions, cannot be integrated. Scholars offer diverse opinions on this matter. The purist argues for philosophical consistency, upholding the notion of paradigmatic and methodological incompatibility. The dialectical position, on the other hand, acknowledges the “assumptive sets of different paradigms are different in important ways, but paradigms themselves are historical and social constructions and so are not inviolate or sacrosanct” (Greene 2007, p. 69). This perspective maintains a position wherein the philosophies underlying quantitative or qualitative data collection, however contradictory, are respected, valued, honored, and made transparent. Doing so requires flexibility and self-awareness on the part of the researcher.

Tashakkori and Teddlie (2003), reasoning that the research question is the force driving the methodological approach, found pragmatism to be *the* best philosophical position to anchor MMR. Howe (1988) rejected postpositivism and constructivism as dichotomous constructs, promoting pragmatism as an alternative position wherein researchers move from “whether” to combine to “*how* this combination can be accomplished” (p. 14). Despite thoughtful, informed efforts by scholars to apprise the MMR community of pragmatism’s nuances (see Howe 1988; Tashakkori and Teddlie 2003; Denscombe 2008), what has emerged is a “what works” and “anything-goes” attitude toward pragmatism that fails to adequately inform methodological decisions, techniques, and questions. While beyond the scope of this chapter, our own *conditional incompatibility thesis* (Hathcoat and Meixner 2017) is an attempt to reconcile these tensions and position both seasoned and novice researchers, like Nadia, for success.

Returning to the dialectical ideal, there is one more thing for the reader to ponder in light of the tensions articulated above: *the mental model* – a “set of assumptions, understandings, predispositions, and values and beliefs with which a social inquirer approaches his or her work” (Greene 2007, p. 53). We perceive the mental model to prescribe philosophical stances, meaning that particular aspects of research are unjustifiable absent philosophical position taking. Does research happen without philosophical consideration? Yes, it does. However, this assumes philosophical agnosticism (Hathcoat and Meixner 2017), which can endanger various facets of the research design, most especially the interpretation phase. Let us imagine, for instance, that Nadia is unwittingly steeped in a postpositivist perspective with little awareness of a constructivist epistemology. What are the repercussions, covert and explicit, of embedding interviews into an experimental design? Might she attempt to ascribe deterministic, empirical dispositions to make meaning of her data despite it being inconsistent with an espoused philosophical stance?

We recognize that these are tedious issues to consider, especially for a scholar new to MMR. However, we would argue that the cost of approaching MMR without

considering philosophical positions could outweigh the benefits. The reader, thus, is advised to think critically about her own mental model, contemplating how beliefs, experiences, and biases may color her ability to take a dialectical stance, interweave both paradigms and methods, and interpret results in the spirit of the question asked. If approaching MMR through a pragmatist gaze, it is incumbent on the reader to move beyond a “what works” maxim, assuring she understand the philosophy’s rich origins and emerging insights. The issue is not that pragmatism lacks substance, or fails as a paradigm within which MMR can be situated, but that it is often misunderstood. As Cherryholmes (1999, p. 1) cleverly opined, “pragmatism looks simple at first glance. It is ferociously complex.” For a reader inclined to dig into this more, we advise a review of Biesta (2010).

3 Major Approaches

Across the arch of mixed methods research – and during the procedural development period, in particular – scholars have advanced an array of taxonomies and classifications that guide researchers in the design of MMR studies. In his concise, practitioner-oriented primer on MMR, Creswell (2015) agilely distilled the major approaches into three basic designs and three advanced designs. This chapter will reflect on the chief basic approaches (i.e., convergent, explanatory, and exploratory) and the most common of the advanced designs (i.e., intervention). Before doing so, we want to clarify that mixed methods designs can be *fixed* or *emergent* (Creswell and Plano Clark 2018). A medical anthropologist studying the culture of teen pregnancy within a rural locus may design, from the start, a *fixed* study that draws from both quantitative and qualitative methods. Herein, the deficits associated with any one method of data may pull strength from the other method – and vice versa. On the other hand, it is entirely plausible that the same scholar may have begun the study with a focus on addressing a quantitative hypothesis. Imagine, however, that the results contradict extant theory, as well as the researcher’s hypothesis. The researcher may build in a second phase wherein qualitative interviews could help explain the first phase’s curious results. This can be thought of as an *emergent* mixed methods study. The study (Meixner et al. 2013) reviewed above was intentionally *fixed*, prioritizing the use of second-phase focus groups to explore and triangulate survey results.

Before we peer into each of the four major approaches, it is also important to elucidate three methodological decisions that often confuse researchers who are new to MMR: timing, weighting, and mixing. Adapted from the work of Creswell and Plano Clark (2018), each practice is described with relevant examples in Table 2. We stress that the researcher’s choice regarding these practices must (1) align with the research question and (2) cohere with the *fixed* or *emergent* design of the study.

Morse and Niehaus (2009) utilized the term *core component* in reference to the strand that has more weight in any given study; this core is to be thought of as “the backbone...onto which all other components, methods, or strategies will be attached” (p. 23). If a mixed methods study commences with a dominant quantitative strand, that particularly strand should, hypothetically, stand on its own. The logic

Table 2 Common practices within MMR approaches

Practice	Meaning	Example
<i>Timing</i>	This refers to the temporal and ordinal placement of quantitative and qualitative strands. Does one precede the other, or do they happen concurrently?	Jeremiah develops a grounded theory that explores the experiences of persons coping with lupus. If he develops an instrument based on the theory, the timing of the quantitative strand follows the qualitative one
<i>Weighting</i>	This refers to relative priority of strands. Are the qualitative and quantitative strands equally important, or does one support the other? Are both equally or differentially represented in analysis and interpretation?	Maris designs a quantitative survey to gauge perceptions of a mental health intervention. In support of her items, she adds several open-ended qualitative questions allowing participants to explain the rationale for the scores they have indicated. Herein, the quantitative strand has greater priority or emphasis
<i>Mixing</i>	This regards the point where the researcher chooses to integrate the strands. Does mixing happen at the level of design, collection, analysis, and/or interpretation?	In a study on crisis intervention services for sexual assault survivors, Fletcher's team collects survey data and focus group data separately. Each is analyzed according to its research tradition, later merged into a comparison heuristic. Here, the data are mixed at the level of interpretation

follows that the *supplement component* exists to support the *core*; it may not, therefore, be independent. Herein, we can see that MMR is much more than the knitting together of a qualitative study and a quantitative study, as is often the presumption of novice researchers. MMR, rather, is a thoughtful and integrative methodological endeavor.

The practices of mixing, weighting, and timing are sometimes depicted in the literature with symbols and nomenclature. For instance, one's choice to prioritize a qualitative strand over its quantitative counterpart would result in a truncated capitalization of qualitative (i.e., "QUAL") and lowercase, italicized denotation of quantitative (i.e., "*quan*"). Timing decisions can be represented in research articles with arrows (e.g., "QUAL → *quan*" means that a prioritized qualitative strand was followed by a quantitative strand) or plus marks (e.g., "*qual* + QUAN" means that data were timed concurrently, with priority given to the quantitative strand) (see also ► Chap. 40, "The Use of Mixed Methods in Research").

In reference to our research study on barriers to crisis intervention services, the appropriate classification is as follows: [QUAN + *qual*] → QUAL. Data were mixed at the levels of design, collection, and analysis. The first phase (i.e., QUAN + *qual*) refers to the web-based survey, which prioritized the quantitative items. Within the survey, participants were given the opportunity to offer open-ended comments to contextualize their item responses. While the qualitative data were reviewed, our team prioritized a statistical analysis premised upon frequentist assumptions. In this regard, the timing of the second strand was deliberate; we utilized the survey

results to inform the development of our focus group protocol. The second QUAL strand was weighted equally to the first phase (i.e., QUAN + *qual*), given the extent to which it addressed the research question and aligned with our goals for the study. To this end, we also employed an intensive qualitative coding, analysis, and interpretation drawn from respected grounded theory techniques (Bowers 1988; Charmaz 2006).

3.1 Convergent Design

The convergent design, also referred to as *convergent parallel*, is as elegant as it is simple, composed of one phase. Timing is concurrent with equally weighted qualitative and quantitative strands that are ordinarily mixed at the level of interpretation (Creswell 2015; Creswell and Plano Clark 2018). Of note, the idea of concurrent timing does not mean that data from the two strands are collected at exactly the same time. It is possible, for instance, for a researcher to deploy a survey instrument and conduct interviews on different days, or weeks, for that matter. Concurrent timing is not an exact measure; it relates more to the intentionality of the design. The strands are regarded as independent, merged after each set of data has been collected and analyzed separately. Then, the data sets are often compared for convergence and divergence.

Kukla, Bonfils, and Salyers (2015) utilized the convergent approach to explore factors impacting work success in veterans with post-traumatic stress disorder (PTSD) or other severe mental illness (SMI). The authors chose this design for “the strength of offering a more comprehensive understanding of the phenomenon. . . in that different, yet complementary, information was sought through qualitative and quantitative methods” (p. 54). Therein, qualitative data (i.e., a survey of factors impacting vocational functioning) and quantitative data (i.e., narrative accounts of work experiences) were collected within one phase and analyzed separately, mixed at the level of interpretation. We might understand the nomenclature of this design as “QUAN+QUAL.” Kukla et al. (2015) reported that the qualitative data corroborated survey findings, with additional insight produced. As the first-published study of this topic, MMR was especially important to the authors, as it evidenced a rich, triangulated picture of the complex factors affecting work successes for persons with PTSD and SMI.

3.2 Explanatory Sequential Design

The explanatory sequential design consists of two phases, always starting with the quantitative, the results from which drive the development of a second qualitative phase (Creswell 2015; Creswell and Plano Clark 2018). This design can be *fixed* or *emergent*; the latter is often precipitated by curious or unexpected quantitative findings that bear further exploration. In the explanatory design, researchers analyze and interpret quantitative data, which informs the design of a follow-up qualitative protocol. Qualitative findings exist to explain results from the first phase, rendering this strand subordinate to its quantitative counterpart. Though “QUAN→*qual*” is standard in this design, there are known deviations. Creswell and Plano Clark (2018)

explore a variant of interest to health social scientists: the participant selection approach (i.e., *quan*→QUAL). In this approach, let us imagine that researcher plans to explore a phenomenon that requires a diverse, purposive sample. She has access to a database that allows for her to select, and later invite, participants with different scores into her primary study. Thus, the quantitative data exist, in this case, to select participants into the qualitative phase.

Restall and Borton (2009) employed an explanatory sequential design (e.g., “QUAN→*qual*”) to apprehend the prevalence of parental concern about their children’s development at the point of school entry. Broadly, this study reflected a desire to support child development in Canada, within which, at the time of study, there were “no guidelines for the systematic screening of children so little is known about the extent of developmental problems in young children or parental experiences in addressing developmental concerns” (p. 208). To address their quandary, the researchers first surveyed parents utilizing the Parents’ Evaluation of Developmental Status (PEDS; Glascoe 2004). Data ($n = 290$) were analyzed, and a select cadre of parents was identified (i.e., of children in the moderate- or high-risk categories with variable health services) for phenomenological interviewing ($n = 9$). Of the value of this MMR design, the study underscored the importance of juxtaposing data on prevalence of parental concerns across varied domains (e.g., expressive language, social-emotional, school and health) with a narrative elicitation of parental concern about their children’s development. Further, the study allowed the researchers, in the qualitative strand, to employ a heterogeneous sampling technique.

3.3 Exploratory Sequential Design

The exploratory sequential design, comprised of two or three phases, commences with qualitative data collection and proceeds to an instrument or intervention development process that is then tested quantitatively (Creswell 2015). Remarking on the nuanced challenges of this approach, Creswell (2015, p. 40) stated:

With three phases, it also becomes the most difficult of the three basic designs. Like the explanatory sequential design, this design takes times, but these phases are extended out in time much more than the other basic designs. This design is also challenging to conduct because of the difficulty in taking qualitative results and turning them into a new variable, a new instrument, or a new set of intervention activities.

Historically, the design was referred to as two-phased (Creswell and Plano Clark 2011), which lingers in some MMR circles. Therein, the core intent was to generalize first-phase qualitative findings, such as a grounded theory, through a follow-up quantitative study. Weighting and prioritizing of strands depends on the goal of the study. If the researcher’s intent is to develop and refine a theory or taxonomy, for instance, it is plausible to consider the study as follows: “QUAL→*quan*.” If developing an instrument or assessment, on the other hand, it is reasonable to consider the first phase as subordinate to the second (e.g., “*qual*→QUAL”).

Asante, Meyer-Weitz, and Peterson (2016) used a two-phase exploratory design (e.g., “QUAL→*quan*”) to investigate mental health and health risk behaviors of Ghanaian homeless youth. As the topic had not been explored in an African context, the authors began with a qualitative inquiry ($n = 16$) into reasons for engagement in risky behaviors. These data informed a quantitative survey ($n = 227$) wherein the investigators looked at clustering effects and predictors relative to the identified behaviors. As the authors incisively reflected, “the qualitative data and results enabled participants to provide views regarding health and wellbeing, while the quantitative data explores the extent of such problems and their determinants” (p. 436). In this study, neither a new instrument nor intervention was developed; rather, the qualitative phase appeared to have been influenced researchers’ selection of existing, internationally validated measures.

A study by Hansen, Okolonko, Ogynbajo, North, and Niccolai (2017) used an exploratory sequential design to “examine acceptability of and perceived facilitators and barriers to HPV vaccination at [school-based health centers] among parents and adolescents” (p. 706). The study bears similarities and differences to that of Asante et al. (2016). Similarly, Hansen et al. (2017) sought to explore a phenomenon around which extant literature offered insufficient depth or explanation. Differently, the authors developed a survey based on the results of the qualitative strand and utilized the results from both strands to address the core question. First, they conducted in-depth interviews with parents ($n = 20$) and adolescents ($n = 20$) until they reached thematic saturation. Then, they developed a web-based survey based on key themes from the qualitative segment. The survey was piloted and administered to parents only ($n = 131$). Data appear to have been weighted equally (e.g., “QUAL→QUAN”). While the authors describe the study as two-phased, Creswell (2015) would likely consider this a three-phased design. Hansen et al. (2017) collected qualitative data, used those data to develop an instrument, and gathered quantitative data using the newly designed survey.

3.4 Intervention Design

Creswell (2015) introduced the intervention design, also referred to as the experimental design (Creswell and Plano Clark 2018), as an addendum to a previously conceptualized embedded design (Creswell and Plano Clark 2011). Within this design, one conducts a quantitative experiment – or an intervention – that includes a qualitative strand. Let us imagine that we are testing a new therapy designed to help individuals diagnosed with panic disorder. Participants are randomly assigned to three groups: *new* intervention, *status quo* therapeutic intervention, and *no* intervention. Pre- and post-measures consist of a battery of items drawn from psychometrically robust instruments. As the reader might imagine, a design of this nature has its limitations, among them the rival hypotheses about causal processes leading to the results. Qualitative inquiry may yield valuable insights, allowing for a clearer picture of participants’ therapeutic experiences.

The intervention design, adding to one or more of the basic designs explored above, allows for the collection of qualitative data before an intervention (i.e., exploratory sequential), during the intervention (i.e., convergent), or after the intervention (i.e., explanatory) (Creswell 2015). Throughout the intervention period, for instance, the researchers may invite participants to engage in brief interviews or even journal about their experiences. In another variant, researchers may conduct a quantitative-only intervention that yields results into which they hope to elicit depth. This could point to an emergent explanatory sequential design.

Curry et al. (2017) reported upon a 2-year intervention designed to improve five facets of performance in ten hospitals: learning environment, senior management support, psychological safety, commitment to the organization, and time for improvement. Using two surveys and a morality measure, each mapping to different outcomes (i.e., changes in organizational culture, uptake of evidence-based strategies, and mortality rates), measures were taken at baseline, 12 months, and 24 months. What made this a mixed methods study was the collection of qualitative interview data at baseline, 6 months, and 18 months; this was intended “to enhance the assessment of culture change with greater validity than possible with only quantitative data” (p. 3). In addition, the researchers used ethnographic observations at baseline and at 18 months. Of note, all forms of data appeared to have been prioritized in the integration process; furthermore, the qualitative analyses were conducted with adherence to strong standards, including the use of iterative and multi-rater coding. Among the contributions of this study is its attention to how mixed methods – most especially the embedded qualitative strands – enhanced the researchers’ understanding of a complex issue. Curry et al. (2017) opined, “. . . although the quantitative magnitude of changes in culture was relatively modest, the qualitative experiences were compelling, a finding we attribute in part to the difficulty of quantitative measurement of nuanced concepts such as culture” (p. 8).

3.5 Hybrid Design Choices

As the reader might have already conceived, not every mixed methods study fits squarely into one or more of the models denoted above. Two studies serve as examples. The first is a four-phase study that examined counselor and client perceptions of the authors’ emergent approach to treatment, neuroscience-informed cognitive behavior therapy (nCBT) (Field et al. 2016, 2017). To test the approach, the authors merged qualitative (*qual*) with quantitative (QUAN) data at four time periods (i.e., baseline, 3, 6, and 12 months). Peering into the fourth phase of data collection (12-month interval) was of intrigue, as the authors “followed an explanatory sequential process whereby the qualitative data were connected to earlier merged quantitative data to better understand initial quantitative findings” (Field et al. 2017, p. 354). That is, quantitative data – with supporting qualitative items – were collected during phases one, two, and three. At the fourth phase, only qualitative data were collected, via open-ended survey questions, to help the researchers better understand the effectiveness of

nCBT. These data allowed for development of a pathway that depicts client and counselor expectancy development for nCBT treatment.

Kovacs Burns et al. (2014) utilized a hybrid approach to determine the resources and supports needed for constituents (e.g., patients, families, providers) to engage in patient-centered decisions with an overarching intent to “improve access, quality, safety, and sustainability” (p. 234) of a Canadian healthcare model. Four objectives were mapped to distinct phases, independent though amalgamated across the arc of the study. Phase one entailed a need assessment, wherein constituents were interviewed individually or in groups. Results were used to guide the second and third phases. Phase two was comprised of a systematic literature review (qualitative), used also to inform phase three’s development of a draft resource kit that was tested, through qualitative and quantitative means, in phase four with some of the same individuals who participated in phase one. The approach, deemed “practical and significant for this type of study” (p. 244), was intentionally integrative. While the authors did not discuss relative weighting among components, a hypothetical diagram for this study might be: [“QUAL+quan” *needs assessment*]→[“QUAL+quan” *systematic review*]→[“QUAL+QUAN” *intervention*]→[“QUAL+QUAN” *evaluation*].

4 Getting Started

Getting started on a mixed methods project entails multiple considerations. One of the best ways to begin is by reviewing mixed methods studies published within one’s own discipline or field. Therein, one can appraise research studies of interest, contemplating some of the seminal issues that we vet in this chapter, such as: How does a mixed methods approach address the research question in a more robust way than a qualitative or quantitative study could do on its own? What are the philosophical underpinnings of the study – and in what ways were these rendered transparent or considered in the integration of qualitative and quantitative data? How were the data mixed, weighted, and timed? Does the design reflect one of the better-known classifications, or did the authors utilize a novel approach? Were the data integrated and discussed in a coherent, systematic manner? As Morse and Niehaus (2009) summarily stated, “the more you know about research methods, the easier mixed methods will be!” (p. 77).

We would argue that reflection into one’s own skills, biases, and mental models is an integral precursor to all social science research. MMR is no exception. An individual whose worldview is inherently constructivist should not be dissuaded from engaging in MMR; instead, that researcher is advised to think critically about how her epistemological, ontological, and methodological stances might flavor the collection, analysis, and integration of qualitative and quantitative data. Correspondingly, one would not unwittingly situate an MMR study under a pragmatist guise without having considered how philosophy guides method, data, and design. Furthermore, doing MMR well requires expertise in quantitative and qualitative approaches, but this does not imply that the reader has to be *the* specialist in both areas. Indeed, it is rare to discover solo-authored mixed methods studies, in part because so many researchers partner with colleagues whose skill sets complement their own.

Expanding on the importance of reflection, Morse and Niehaus (2009) underscored thinking and planning in the context of what they call “the armchair walkthrough” (p. 78) – which takes place well before one starts a study. Herein, a researcher reflects on hypothetical variations of the envisioned study. Start with “if” thinking (e.g., “If I pursue this research question, what approach might I take? If this is the best approach, who comprises my sample and what methods do I consider?). Walking through a hypothetical approach to the research project provides an opportunity to envision multiple pathways, navigate plausible dilemmas or obstacles, identify research partners, contemplate a timeline, and interrogate the extent to which MMR is (or is not) the best approach.

Creswell et al. (2011), writing for the National Institutes of Health (NIH), acknowledged that while there “is no rigid formula for designing a mixed methods study” (p. 6), researchers are advised to consider several steps. Once the above-noted preliminary considerations (e.g., philosophy) are resolved, and the goals of the study are clear, the researcher should determine methods; select the design best aligned to the goals and question (e.g., exploratory); collect, analyze, and integrate qualitative and quantitative data in accordance with the design chosen; (4) make meaning of how mixed methods provides the most robust understanding of the phenomenon under investigation; and write the report in such a way that not only the research question is better understood but that the reader walks away with a greater appreciation for MMR (Creswell et al. 2011) (see also ► Chap. 40, “The Use of Mixed Methods in Research”).

5 Conclusion and Future Directions

As with quantitative or qualitative methods alone, MMR is not without its limitations. As noted above, lack of methodological expertise can jeopardize data collection, analysis, and integration; thus, we recommend the cultivation of a research team. Given the transdisciplinary and interprofessional nature of the health social sciences, such a team may not only be diverse with respect to methodological prowess but also with regard to disciplinary and clinical experience. Researchers are also advised to be mindful of time and resources; since MMR entails multiple phases or strands, a study may take longer than one might ordinarily anticipate. Finally, we recommend attending as much to interpretive issues as one would to the design itself. In our experience, novice mixed methods researchers often “lose steam” at the time during which analytical power is most important – the integration of data sets in order to arrive at a full-bodied interpretation.

In spite of these limitations, MMR offers a strategic, innovative, and methodologically diverse approach to investigating health phenomena. Specifically, MMR “reflects the nature of the problems facing public health, such as disparities among populations, age groups, ethnicities, and cultures; poor adherence to treatment thought to be effective; behavioral factors contributing to disability and health; and translational needs for health research” (Creswell et al. 2011, p. 2). In other words, the very methods used, like the thoughtful juxtaposing of critical

ethnography with survey research, may allow for inquiry into a third-world health epidemic that holistically, ethically, and carefully considers the character of the research itself.

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Recruitment of Research Participants

5

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Contents

1	Introduction	72
2	Investigator: Participant Interface in Recruitment	73
2.1	Researcher's Expectation and Personal Perspective	73
2.2	Expectations of Research Participants	73
3	Barriers and Facilitators to Participant Recruitment and Retention	74
3.1	Barriers and Challenges in Recruitment	74
3.2	Facilitators of Recruitment	75
4	Recruitment Strategies	77
5	Recruitment of Children and Adolescents	79

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5.1	Utilization of Midwives, Child and Family Health Nurses, and Childcare for Recruiting Newborn and Infants	80
5.2	Utilization of Schools for Recruiting Older Children and Young People	80
6	Recruiting Adults into Health Research	81
6.1	Approaching Adults	82
7	Recruitment of Older Adults	90
8	Recruitment of Difficult-to-Reach Communities and Medically Compromised People	92
8.1	Community Ownership	92
8.2	Incentives and Acknowledgments	93
8.3	Setting	93
8.4	Several Means of Contact	93
8.5	Recruitment of Medically Compromised Groups	94
9	Conclusion and Future Directions	95
	References	95

Abstract

Successful recruitment and retention of study participants are essential for the overall success of a research study. The recruitment process involves identifying potential research participants and providing them with the information to establish their interest to join a proposed research study. Research studies are often time and labor intensive, and inappropriate recruitment of research participants can significantly impact the study findings. This chapter will introduce readers to a range of associated issues and offer possible solutions and mitigation strategies to enhance research participant engagement. First, this chapter describes the issues surrounding investigators' and potential participants' expectations related to their involvement in research. Next, the chapter will identify the facilitators, barriers, and challenges associated with recruitment and retention of participant. Then, the chapter will highlight some traditional and modern recruitment and retention techniques, for participation in health research across the life course: children and adolescents, adults, and seniors. Last, the chapter will detail the specific attention, resources, and sensitivity required to maximize recruitment and retention when conducting research with specific population groups such as minority populations and medically compromised people.

Keywords

Recruitment strategies · Study participants · Participant engagement · Participation · Target population · Minority recruitment · Opt in–opt out

1 Introduction

Recruitment of participants in health research can be challenging. An appropriate selection of participants is essential for accurate representation of the population of interest. However, poor recruitment is still a significant drawback for many studies (McDonald et al. 2006; Glasser 2014). Recruitment can be defined as a “dialogue between an investigator and a potential participant prior to initiation of the consent

process” (Patel et al. 2003, p. 229). The recruitment process involves identifying, targeting, and enlisting potential participants, followed by provision of information to potential participants and establishing their interest in the proposed study (Patel et al. 2003). To ensure appropriate recruitment in a quantitative research project, for example, it is important to identify participants that closely represent the target population and meet the sample size and power requirements of the study (Hulley et al. 2013). Thus, it is important to identify appropriate environments to gain access to the intended population. Overall, the recruitment process depends on the type of research, collaboration between researchers and the recruitment/referral pathway (e.g., clinicians), characteristics and preferences of participants, and the strategies employed for recruiting (Patel et al. 2003). This chapter describes the issues surrounding investigators’ and potential participants’ expectations related to involvement in research, the facilitators, barriers, and challenges associated with recruitment and retention of participants and explains the process of recruitment across the life-span and in various population groups.

2 Investigator: Participant Interface in Recruitment

2.1 Researcher’s Expectation and Personal Perspective

Prior to initiating any study, it is essential to consider the relevant roles, responsibilities, and interactions of the primary parties involved, that is, the investigator, who asks scientific questions, and the participant, who consents to answer scientific questions put forward by the investigator (Rodriguez et al. 2003). Both the investigator and the participant have preconceived expectations from the relationship that they will be establishing and how it will progress. The investigator goes through an extensive process before a study begins that shapes expectations about recruitment. This includes developing a research protocol, participant information sheets and consent forms, and review and approval by relevant scientific and ethics committees. The investigator expects to recruit participants that closely match the target population and aims to achieve the defined sample size. In the co-author’s own words regarding a researcher’s expectations toward participant recruitment:

I have over 1,000 participants to recruit; in that case, I would love to have easy access to my potential participants so that I am closer to my estimated sample size without delaying my study timelines and budget. (Arora)

2.2 Expectations of Research Participants

Participants also have expectations from the study investigator(s) and from the research study they join. It is expected that a research participant will be assertive and protect their own rights, which will actually improve the quality of research that they are enrolled in (Rodriguez et al. 2003). Potential research participants should have

access to detailed information about what they are consenting to (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). This will inform their expectations:

- To be informed about the potential benefits and harms associated with the planned research; and if they are ill, then how will this research help them
- To ensure that their interests are protected. That is, a clear explanation of what is involved and what they will have to do, who will be in charge of their health interests, any safety standards in place to protect them from harm, whether the research has been reviewed and approved by relevant committees, whether they have to spend money out of their own pocket or will be compensated for taking part, whether they have the right to withdraw from the study without prejudice, and whether the results will be shared with them upon study completion
- To have some understanding about the study design and leadership. That is, who designed the protocol and whether it is well designed, whether the investigator is competent to undertake the research, why the research is important, who else is involved, and whether any community advocate was involved in the design and review of the research
- To be informed if there is any conflict of interest or controversy associated with the study, if a similar study has been done before, any financial beneficiaries, and the self-interest of the investigator

3 Barriers and Facilitators to Participant Recruitment and Retention

Problems with recruitment can adversely affect the timeline of a study, increase workload, compromise the study findings, and eventually lead to study abandonment (Patel et al. 2003). Despite the extensive recommendations for improving participants’ recruitment in research (Caldwell et al. 2010), poor recruitment remains a fairly common and costly issue.

3.1 Barriers and Challenges in Recruitment

The following list illustrates barriers or challenges for recruitment in any study (Liljas et al. 2015; Stein et al. 2015; Quay et al. 2017) and has been categorized into “researcher- and trial-related” and “participant- and treatment-related” factors.

3.1.1 Researcher- and Trial-/Protocol-Related Factors

- Risk of test therapy/uncertainties inherent in investigational drugs
- Perceived risk associated with randomization
- Clinical visits required
- Systemic therapy involved
- Added stress from trials
- Additional tests required

- Fatalism
- Variations in Institutional Review Board (IRB)/Ethics Committee regulations across partnering institutions
- Culture or language related: language (lack of study materials and communication in target populations' language) or cultural issues (e.g., lack of respect for gender or segregation, religious practices)
- Logistics: under-presentation of ethnic population at recruitment sites, costs associated with elevated recruitment requirements, limited time to recruit or requirement for repeated recruitment efforts, the absence of a care coordinator, ineffective informed consent processes, and unfeasible study and recruitment goals
- Study design: lack of appropriate (racial/ethnic/language specific or validated) assessment tools, narrow entry criteria, and recruitment based on convenience
- Awareness: stereotypes about difficulties of engaging with different racial/ethnic population groups, researcher attitudes (e.g., apathy), ineffective guidance to study staff, and limited knowledge about methods to promote a study, recruit, and retain participants.

3.1.2 Participant- or Treatment-Related Factors

- Disinterest or lack of feeling of belonging: immigrant perceptions of not belonging to society meant to benefit from the proposed research, lack of interest, misgivings about scientific importance or benefit, prior treatment for disease (trial participation perceived as unnecessary), and utilization of disease-specific services (e.g., diabetes services)
- Conflict: decisional hierarchy and gender, substance abuse or mental health issues, and religion or cultural conflicts
- Education or training related: poor understanding of research intentions among community or religious leaders and lack of understanding about the consent process
- Logistic or opportunity costs: potential costs associated with participation, time spent away from work, travel time, family and other commitments, and logistical issues related to transportation or location
- Fear or inhibitions: fear of being reported to immigration, stigma of being labeled with a health condition, concerns about adverse effects (i.e., related to interventions), fear of finding out health issues, mistrust of research, previous poor experiences participating in research, conservative attitude toward risk-taking, unique health situations, and no or limited health insurance.

3.2 Facilitators of Recruitment

A range of recruitment interventions can be adopted to improve participation in research (Mapstone et al. 2007), for example, changing aspects of the design (e.g., not including a placebo group) (Welton et al. 1999), making the participant's experience in data collection easy and simple, providing monetary incentives for

participants (must be balanced with the ethical considerations of economically disadvantaged participants), and engaging collaborators and developing referral pathways via newsletters to provide updates on study progress. The major facilitators to health research participation can be categorized into (i) design and logistics, (ii) benefits and low risk in participation, (iii) altruism, and (iv) family approval and community involvement; these will now be described in detail below.

3.2.1 Design and Logistics

During the planning and designing phase of any study, it is advisable to hire staff to whom participants can relate (e.g., same racial/ethnic background as the target population, insider approach) (Hayfield and Huxley 2015; Stein et al. 2015; Manohar et al. 2017). This is because most racial/ethnic or marginalized population participants can communicate effectively and comfortably in their own language and rhythm of expression (Liamputtong 2010; George et al. 2014), thereby improving recruitment by establishing a level of trust. For instance, in a study involving immigrant Filipino women, the investigators noticed that the potential participants were more likely to provide consent if they personally knew the recruiter (Maxwell et al. 2005). Similarly, in a study involving recruitment of transgender participants (Owen-Smith et al. 2016), participants felt that research staff who are not a transgender himself/herself would not be able to effectively connect with them.

However, there is also always a risk of exploitation which needs to be considered (Brugge et al. 2005). Furthermore, language-appropriate material should be available so that potential participants can understand their involvement (Arora et al. 2017b). Also, it is important that the recruiting staff are well informed about the study and appropriately answer potential participants' queries; otherwise, low recruitment is a potential outcome.

In terms of logistics, it is advisable to facilitate participants' involvement by providing free parking or by utilizing a study site close to public transport. It is also important to provide flexibility in scheduling participation on weekdays, weekends, and afterhours where possible, as this will facilitate active participation without compromising participants' daily routines. Furthermore, participants should be provided different options for obtaining recruitment approval (e.g., in person, phone, postal mail, and/or email) (Owen-Smith et al. 2016). Last, the research staff should acquire employer support where applicable (for the potential participants) to take time off from their work for participation (Wyatt et al. 2003).

3.2.2 Benefits and Low Risk in Participation

Incentives play an essential role in improving recruitment rates and can include money, transport cover, complementary refreshments, gift vouchers, health checks/examinations, or access to healthcare facilities (Liamputtong 2007, 2010; George et al., 2014). Incentive choice has been reported to be desirable by many potential participants (Owen-Smith et al. 2016). Certain marginalized population groups, such as transgender individuals, are willing and motivated to participate in research (relevant to their population group) in order to receive information on the latest

scientific developments on their health, interact with fellow community members, and receive free medical services (if part of a study) (Owen-Smith et al. 2016).

Furthermore, it has been observed that a high level of detail on the risks and safeguards associated with the intended research can serve as a facilitator for recruitment (Farmer et al. 2007). Additionally, studies which are noninvasive, or have the least risk of discomfort, such as questionnaire-based surveys, educational interventions, or minimal intervention-related health risks, tend to have better recruitment rates (Sengupta et al. 2000). Those individuals who are terminally ill (such as stage 4 cancer patients) and have no other treatment options available except the proposed “test therapy” are often willing to participate as they feel it is the last resort (Lee et al. 2016).

3.2.3 Altruism

Altruism is defined as the “willingness to do things that bring advantages to others, even if it results in disadvantage for yourself” (Satar et al. 2015, p. 271). Such ambition is quite evident in studies targeting particular racial/ethnic or marginalized population groups. For example, Owen-Smith et al. (2016) reported that many of the recruited transgender participants felt motivated to join the study to contribute to research which might benefit their respective community and possibly provide essential data to fill knowledge gaps and to share their information with the scientific community. Lee et al. (2016, p. 4) identified altruism as one of the important facilitators for recruitment in their clinical trial and stated that the participants saw trials as a “way to advance treatment for others.”

3.2.4 Family Approval and Community Involvement

Opinion and approval of family (sibling, spouse, child) and friends serve as a significant facilitator for recruitment in research (Giarelli et al. 2011). Such an influence was evident in a recent clinical trial conducted in Asian women suffering from breast cancer. In that study, a significant number of participants cited that if the opinions of family members and friends were positive, they will certainly join the trial; however, if the opinions were negative, they would not be a part of it (Lee et al. 2016). Likewise, in certain indigenous population groups, community mediation is integral for research participation, and its decision (either approval or refusal) will be taken as a facilitator or barrier to recruitment (George et al. 2014). Hence, in such cases, it is very important to seek community elder’s endorsement in the intended research.

4 Recruitment Strategies

A wide range of recruitment strategies can be adopted to facilitate participant engagement and enrolment in research. The strategies employed will depend on factors such as the study’s intended target population, the study size (number of participants and recruitment sites), the study and intervention design, ethics approval

processes, and the recruitment budget. Below, we detail several online and offline recruitment strategies that can be adopted in research.

More traditional recruitment means can be effective if designed, coordinated, and distributed strategically. For example, clear, simple, and well-designed letters and mail-outs (either via post, e.g., the electoral roll, or email, e.g., listserv), flyers, posters, and pamphlets can increase awareness of a study. Newsletters can also help to maximize retention in studies or foster engagement in future studies (Bower et al. 2014).

Moderate- to large-sized research studies benefit from a comprehensive and well-coordinated marketing campaign. This can often be organized and planned with the assistance of media units at the university, institute, or hospital that the study is being coordinated at. Marketing strategies will often include a media release and targeted calls to local print media (i.e., newspapers), radio, and television for further study promotion. Paid advertisements can be placed in classified sections of local papers (such strategies are particularly effective for the recruitment of older adults) (Martinson and Hindman 2005).

Grassroots and community outreach approaches are popular and successful methods of engaging potential study participants. Well-promoted public lectures, seminars, or stalls at supermarkets or local fetes can be an effective way of increasing public awareness of research that can also enable news of a study to spread via word of mouth. Stalls at special interest exhibitions, with recruitment and enrolment of people onsite, are particularly effective for recruiting populations suffering from uncommon disease conditions (e.g., people with coeliac disease have been successfully recruited from gluten-free expos) (Chiu et al. 2016).

Clinical cohorts are often recruited via healthcare referral pathways. A comprehensive and engaged network of clinicians is essential for these strategies to work. Clinical trials may have a number of participating hospital sites, and a range of specialist clinicians involved in the trial may refer potential participants to a participating hospital for screening from their private rooms or other hospitals. General practitioners (GPs) or family doctors can be engaged to refer patients. GP referrals are best facilitated by simple eligibility criteria, a strategy whereby referrals reduce practitioner workload, patient incentives, and involvement of a discipline champion (Ngune et al. 2012). Similarly, community-based healthcare workers (e.g., social workers or community nurse consultants) may identify and refer potential participants into trials.

Online methods for recruiting research participants have become increasingly popular. A comprehensive online marketing strategy for a new study can include targeted social media campaigns (e.g., via Facebook or Twitter), search engine marketing (e.g., Google AdWords), display advertising (e.g., web banners), and mobile advertising (e.g., via apps). Advertising through existing online communities is also an effective means of recruitment, for example, Craigslist (2017) and Facebook groups and pages (particularly for a disease focus area, e.g., Younger Onset Dementia Support Group 2017; Endometriosis Australia 2017). Some countries have online portals where potential participants can browse through and sign up for studies that are open for recruitment (e.g., Join Dementia Research, UK (Join

Dementia Research 2017), Clinical Connection, USA (Clinical Connection 2017), ResearchMatch, USA (ResearchMatch 2017)). Having an online point of engagement for people to find further information about the study (e.g., study website, Facebook page) can enhance recruitment.

Clinical trial recruitment agencies are emerging as a one-stop shop for online recruitment of participants and are becoming increasingly popular. Agencies, such as Trialfacts (2017), offer complete recruitment packages combining a mixture of online media strategies (e.g., social media campaigns, search engine marketing) together with a media release and online newscaster approach (i.e., feature pieces in online news articles) that have a call to action which funnels people into an online screener. Potential participants can learn more about the study and complete a web form to assess their eligibility for the trial. Their information is then forwarded to the research team for assessment and follow-up contact.

Thus far, we have discussed participant and researcher expectations in recruitment of study participants, facilitators and barriers in recruitment of research participants, and recruitment strategies. The rest of the chapter will discuss recruitments of potential research participants from different groups.

5 Recruitment of Children and Adolescents

Accessing and recruiting children and young people in any research is challenging and consists of a number of anticipated and unanticipated ethical complexities, dilemmas, and issues. Any research involving children and adolescents should ensure that their opinions and assistance are sought prior to project commencement since their perspectives may impact the research design (Hibberd 2016). Ethics is critical in every research study; however, if a project involves children and young people, it needs to justify certain prerequisites before being considered for research ethics committee approval (UCL Research Ethics Committee 2016):

- Is the planned research study important for the health and well-being of children and adolescents? Does it really need to be done?
- Is the participation of children and adolescents important to answer the research question or can the intended information be obtained in other ways?
- Is the study method appropriate for children and young people?
- Do the circumstances in which research is conducted provide for the physical, emotional, and psychological safety of the child or adolescent?

In any research, informed consent is a vital part of the recruitment process (see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”). Informed consent is based on the Declaration of Helsinki, which applies to all human subjects, adults and children. In relation to children, consent of the child and adult guardian should both be sought: “When the subject is a minor, permission from the responsible relative replaces that of the participant in accordance with national legislation. Whenever the minor child is in face able to give a consent, the minor’s consent must

be obtained in addition to the consent of the minor's legal guardian" (World Medical Association 2001, p. 374).

5.1 Utilization of Midwives, Child and Family Health Nurses, and Childcare for Recruiting Newborn and Infants

Depending on the study design, if the aim of research is to recruit newborn children, an innovative recruitment approach is to utilize the services of midwives or child and family health nurses (CFHN) (Arora et al. 2012). Midwives are probably the first health professional that new mothers come in contact with, and they provide maternity care to the majority of women worldwide (Johnson et al. 2015). This contact allows them not only to deliver key health messages but also to recruit potential mother-infant dyads. Furthermore, the CFHN serve as a first point of contact between postpartum mothers and health professionals (Arora et al. 2012) and can connect effectively, efficiently, and with trust, respect, and safety to families (Ramsden 2002). In regard to recruiting infants, it is estimated that every second child in Australia attends formal childcare for an average of 28 h per week (Australian Government Productivity Commission 2015). The childcare staff share a close association with the families and work effectively to develop a healthy lifestyle for infants. Hence, childcare serves as an ideal venue to successfully recruit infant-parent dyads.

5.2 Utilization of Schools for Recruiting Older Children and Young People

Schools can serve as a valuable venue for recruiting research participants such as children, adolescents, as well as their parents. Childhood and adolescence are very receptive stages of life; hence, effective health promotion or intervention initiated at these development stages will have great benefits. Furthermore, primary and secondary schools have significant power to influence child/adolescent decision-making capabilities at their respective ages (Walsh 2011). The advantages of school-based research are:

- (i) The researcher can obtain a diverse range of participants from a target population (Mishna et al. 2012).
- (ii) It provides better retention rates compared to other recruitment methods, since school attendance is mandatory.
- (iii) It improves participation by easing the suspicions among student-family populations since potential participants trust the school administration which may transfer onto the study also (Bruzzeze et al. 2009).

Research participation can be further improved by including a school staff member in the recruitment process, especially among underserved populations

(Alibali and Nathan 2010). If research is conducted on the school premises, students are already at the site, saving the allocated research budget. Schools may be incentivized to participate through some remuneration or small fund (Mishna et al. 2012).

A number of strategies can be employed for recruiting children or adolescents in a school-based research study. Research team members should thoroughly explain the proposed study and its benefits, address participants' concerns and queries, and obtain contact information through sign-up forms to facilitate follow-up. This process alongside consent form completion may facilitate interaction between researchers and parents/guardians and improve recruitment rates (Berry et al. 2013; Daley 2013). To make recruitment more attractive, refreshments may be arranged, and research team members can answer questions and guide the participants, parents, and school personnel. Furthermore, recruitment can be enhanced by promoting or advertising the study at parents-teacher meetings; the presence of the research team at these meetings reflects the school's support for the project (Bartlett et al. 2017). Additionally, hiring a parent who has participated in an earlier phase of the same research can greatly assist in building trust in potential participants. Involving a school staff as a faculty sponsor or navigator (Bartlett et al. 2017) also improves recruitment rates. Such school-based navigator can assist in identifying and enabling contact with potential participants, demonstrate endorsement of the project, build trust of students and parents toward the research team, and promote participation (Bartlett et al. 2017). If the target population consists of adolescents from vulnerable populations, it is a viable strategy to employ recruiters and interventionists who serve as "insiders" in view of the target population (Craig et al. 2014).

6 Recruiting Adults into Health Research

There is a lack of evidence to guide the best strategies for recruitment of adults in health research, as few studies explore or fully report on the effectiveness of their recruitment strategies. In quantitative research, when designing a recruitment plan for adults, as for any target group, it is important to identify strategies that are most likely to result in a representative sample. If this is not done, then external validity is reduced and study results are less generalizable to the wider population (Liangputtong 2017).

Strategies to recruit adults into health research should, therefore, be tailored to the characteristics of the adult sample being sought. In order to capture the target groups' attention effectively, it is important to ask yourself:

- Who are your target adult population?
- What are their characteristics (e.g., gender, age, employment status, ethnicity, etc.)?
- Where are they likely to congregate?

Then think about methods of contact that may appeal to this group. For example, selected recruitment methods may need to be different for young adults versus middle-aged or older adults, unemployed adults versus employed, women versus men, English- versus non-English-speaking adults, adults from low versus higher socioeconomic status backgrounds, and those from different ethnic backgrounds.

You will also need to tailor your recruitment strategies as per the design of your study. It is important to consider how much of a burden you are imposing on your participants and how you might be able to encourage their participation, without coercing them into participating. It may be particularly challenging to recruit certain subgroups of adults such as working or caring adults who have busy schedules or adults lacking basic needs, as other priorities are often above participating in your study. Flexible and creative ways to attract and incentivize such adults will likely be necessary.

Joseph and colleagues (2016) identify five elements of successful recruitment:

1. Leveraging pre-existing social networks and personal contacts
2. Identification of community gatekeepers and fostering collaborations with them
3. Creating maps/lists of recruitment platforms and settings/locations
4. Developing concise recruitment materials
5. Developing trusting and respectful relationships with potential participants

6.1 Approaching Adults

6.1.1 Consulting the Target Adult Group

If there is a specific group of adults that you are trying to reach or a specific location that you are attempting to recruit adults from, consultation early on with the potential target group is worthwhile. This could be done by identifying an organization that individuals are commonly associated with or an individual who is well connected in the network of adults you wish to recruit (a “champion” or “gatekeeper”). During consultation, the following should be explored in relation to the target group, to help design an appealing and relevant recruitment plan:

- The best location of recruitment and study visits
- The best time to approach (and what the factors might be that could affect this)
- The best methods of contact for study invitation
- Who should be delivering the invitation
- Appropriateness and understanding of wording of any invitations (face to face, written or visual materials)
- When a follow-up on an initial invite should be made, how often and through what methods

Recruitment of adults into health research may be directly via the research team or via a third person (e.g., a healthcare professional or community leader). Interaction

with potential participants and effectiveness in negotiating participation are essential in ensuring effective recruitment, whether this is done by the researcher or a third person.

6.1.2 Recruitment Location

Notoriously, researchers recruit adult samples through tertiary education settings by drawing on their students and colleagues, as often students and staff are an easier-to-reach pool of potential participants than recruiting through external locations to education. The issue with this recruitment setting, however, is that skewed samples (e.g., younger and healthier student cohorts) can be recruited, in comparison with the wider population outside of education. Although such convenient approaches can result in large numbers of adhering participants, the applicability of results to the wider population are, therefore, questionable.

Thinking about the target group of adults, it is important to identify locations that are easily accessible and highly visited by your target population. For example, GPs and other health services are regularly used by adults, and so recruitment through healthcare providers may be an effective recruitment avenue. Workplaces often have newsletters and internal mail systems that can be utilized to promote your research. You may need to think creatively about where it is possible to cross paths with your target group of adults, such as places of worship, shopping centers and supermarkets, public transport centers, bookmakers, soccer clubs, and Returned and Services League (RSL) clubs and hotels. If you are delivering an intervention as part of your health research, then recruitment via the location of intervention delivery may be an option, particularly if your intervention is community based. For example, a male-only weight management intervention study in Scotland successfully recruited their required sample ($N = 747$ men) through a combination of professional football club-based activities, media coverage, workplace advertisements, and word of mouth (Wyke et al. 2015). The intervention was delivered via each of 13 professional football clubs by community coaches and included participants from a range of socioeconomic backgrounds. Participating men spoke of being drawn into the intervention because of its setting – the football club that they support and associate with Wyke et al. (2015).

6.1.3 Recruitment Methods

Methods of recruitment will also play a part in the adults that subsequently participate in your research (e.g., recruiting through only passive methods where the interested individual has to make first contact with you, such as newspaper advertisements and through social media, will likely draw a different sample to recruiting through active face-to-face strategies where you make first contact with individuals). Selected methods need to be flexible but also feasible. There is limited evidence that the number of strategies used results in greater recruitment rates of adults into health research, but one would assume that the more strategies used, the more likelihood that the target group will be reached in some way.

The financial budget is often a deciding factor on the methods to be used for recruitment. Recruitment strategies do not have to be expensive to be effective.

For example, research with young Australian adults found that utilizing unpaid online recruitment methods resulted in a greater response rate than paid methods (Musiat et al. 2016). Interestingly, in this particular study, the unpaid methods generally resulted in a sample that were younger and had lower emotional well-being, compared to those recruited via paid methods, highlighting the slight differences in characteristics of samples recruited through different means. Table 1 details different recruitment methods and pros and cons to consider in regard to their use in recruiting individuals into health research.

6.1.4 Recruiting Adults via Healthcare Professionals

If you are recruiting via healthcare, understanding the particular health system and the roles of team members in that system is essential in ensuring that your recruitment strategies can be introduced with as minimal disruption as possible and to effectively capture the target adult audience. Building a strong relationship early on with the healthcare team is essential, particularly if they will be inviting individuals into your study. This might be done by presenting a summary of your research, meeting with team members, and being present on site for informal conversations with the team. Administrative staff may be particularly vital to engage in the process of developing and rolling out of your recruitment strategy, especially reception staff who are the first point of contact with a patient during visits in a health setting. Providing a one-page flow chart, short information sheet, or recruitment card about your study to administrative staff and healthcare professionals may be useful in reminding them about your study and the role they have in engaging patients in your research.

Often, it is a healthcare professional that decides if an individual is eligible to be invited to participate in a study or not, which depending on their investment, understanding and interest in the project can be detrimental or assistive to recruitment rates. Healthcare professionals are busy and have many responsibilities. Thus, promoting your research study may not always be at the top of their priorities. Identifying ways of recruitment to assist healthcare professionals in the screening eligibility process can be extremely useful. For example, consider all team members that may be able to assist in screening for eligibility. Clinicians are often the most time poor. Perhaps nurses or other team members can assist. It might be possible for the research team to actually make the invite once eligible individuals are identified to relieve the expectation of the healthcare team from doing this (e.g., can the research team recruit via face-to-face interaction in the clinic waiting room or draft and send out invitation letters on behalf of the healthcare team).

If you are working with a particular subgroup of adults, then working collaboratively with clinicians and appropriate community organizations (as mentioned earlier, “champions” or “gatekeepers”) can assist in your recruitment. Often, the researcher will still need to drive the recruitment, but working collaboratively with champions expands the researcher’s reach into the potential pool of participants.

Table 1 The pros and cons of different recruitment methods for health research

Recruitment method	Pros	Cons
“Snowball” sampling (initial participants invite others to participate)	Tapping into existing networks so likely to speed up the recruitment process	Samples are likely to be similar in their characteristics and not a representative sample of the wider population
	Utilizing participants to complete recruitment rather than the researcher	Difficult to evaluate success of this method
	Useful to reach individuals that you may not be able to reach through other methods (e.g., homeless individuals, illegal immigrants)	It may take time to establish a strong relationship with initial participants before they commence snowball recruitment
	Useful in qualitative research	Difficult to evaluate success of this method (requires individuals to keep a record of who they have invited and when)
Letters or postcards (either direct from the research team or via third person)	Can be addressed from someone that the individual already trusts (e.g., a healthcare professional)	Costly (print costs and person costs if hand delivering)
	Quick to administer in large numbers if delivering via postal services	Several mail-outs or visits to houses may be required to reach the target sample size
		May be discarded as “junk” mail
		Addresses are needed for mail-out
		Several personnel may be required to deliver invites door to door
Referrals from healthcare providers	Utilize established trusted relationships	A lack of control as to who is invited – the healthcare provider’s role and interest in the research will determine the effort put in to actively promote recruitment
		Difficult to evaluate success of this method (requires the healthcare provider to keep a record of who they have invited and when)

(continued)

Table 1 (continued)

Recruitment method	Pros	Cons
Flyers, pamphlets, brochures, posters	Can be left at convenient locations	Cost (printing and personal time if being distributed by hand) Need to be placed in a prime position to capture attention May need to be replaced often
Videos	Can be played at times when the research team are not present to a wide audience Can be utilized on website, social media, public locations (e.g., general practice surgeries)	Difficult to evaluate success of this method (e.g., how do you capture number of people that have read a poster) Require expertise in creating appealing and high-quality videos May be costly if hiring individuals to participate in the video Difficult to evaluate success of this method (e.g., how do you capture number of people that have read a poster)
Face-to-face recruitment at healthcare provider setting (can go through clinic lists, registers)	Builds rapport with the individual Validation of the research through recruitment at a trusted site (the individual already has a relationship with the healthcare provider) Clinic lists and registers can be used to identify large numbers of eligible individuals relatively quickly allowing a more targeted recruitment approach	Costly (research time) Time intensive (e.g., may require screening from a healthcare professional and face-to-face interactions can take longer than other approaches)

Face-to-face recruitment at community outreach activity	Reach potentially large numbers	Can be difficult to evaluate success of this method
	Builds rapport with the individual	Time intensive May require incentives to attract individuals to your stall if competing with others at a community event
Phone calls, emails, internal mail in workplaces, etc.	Direct access to a large number of individuals via a known third party	A lack of control as to who is invited – reliance on the third party to make initial contact with individuals through their lists (consent will need to be sought prior to researcher involvement) Difficult to evaluate success of this method (e.g., relying on a third person that has access to individual's contact details to record who has been contacted and when)
	Potentially can reach large numbers	Prime time and location can be costly Difficult to evaluate success of this method (e.g., how do you capture number of people that have watched a TV advertisement)
Social media and the web	Highly used by adults of all background	Advertisement needs to be well thought out to grasp attention of the target group (may require payment to be located in a prime position)
	Cost-effective	May require management by research team (e.g., Facebook where posts can be inappropriate)
	Website analytics are useful to guide and manage online strategies Particularly useful strategy for people of low SES, as a large proportion of the population have access to a phone and have social media accounts	

(continued)

Table 1 (continued)

Recruitment method		Pros	Cons
Registries		Access to large number of potential participants	Bias in sample (the most motivated individuals and often those that are well informed and educated in regard to research tend to join registries)
		Immediate contact with the researcher may be possible to build rapport	
		Useful for building community research registries at locations where large numbers of minority groups converge, such as during community health and cultural events	
Word of mouth		Can be successful particularly if participants through “champions” and “gatekeepers” that are enthusiastic about the research	Relying on others to recruit
		Individuals already have a relationship with those inviting them – rapport already exists	
Recruitment through existing research studies		Individuals already have a research-focused relationship with a team known to you (rapport has already been developed)	Difficult to evaluate success of this method (e.g., relying on others to record who has been invited and when)
			Reliance on other research team members inviting participants into your study
			Participant overburden needs considered
			More motivated individuals tend to provide their time again and again

6.1.5 Recruiting Adults Through Existing Databases and Organization Contacts

Research organizations often have websites that can be useful avenues for recruitment. Detailed information on studies can be made available for potential individuals to read at their leisure on such websites prior to making a decision on whether to participate or not. Such organizations often have databases for adults to register their interest in participating in a particular research area or type of research. Other organizations, including workplaces, community organizations, and sports and recreation clubs, may also provide access to the target group. The first point of contact may be someone within the organization or you may be asked to provide a presentation or similar to introduce your research to the target audience.

6.1.6 Flexibility in Location and Timing

For working or caring adults, time can be a constraining factor for participation in research. Flexibility in where visits can occur can ensure better recruitment and retention. For example, if home, work, or other public space visits are possible, which allow the researcher to go to the participant, recruitment and retention rates may increase. Allowing for flexibility in timing of visits will also be important (e.g., outside of work hours and at a convenient time for those with caring responsibilities). For safety reasons, this may mean having two researchers or recruiters available, particularly if it is likely that the recruiter will need to enter the potential participant's home. When working with dyads or family members, extra time in recruitment may be necessary as additional juggling to find a time that all can attend may be required.

6.1.7 Incentives, Compensation, and Acknowledgments

Where incentives and compensation (e.g., for travel, childcare, and so on) are utilized, the timing and size are an important consideration. Providing incentives at the point of recruitment, particularly if they are very appealing, may boost initial motivation to participate in research. However, participants may become less motivated as time progresses, and drop-out rates could be high. On the flip side, if incentives are not provided until the end of study participation, then retention may be poor as participants may drop out early as they have not received an incentive. Compensation should be provided as timely as possible to the study visit, so that the individual is not out of pocket (Robinson et al. 2015).

Incentives used for adults need to be specifically tailored for the adult audience being targeted and within the approvals of ethics. If designing an intervention, then the intervention itself should be designed to be appealing as possible for adults, sparking interest in their own health, to entice their participation. Feeding back on health data collected can be of interest to some participants, such as providing a summary of health information collected as part of the research. The timing of this feedback will need to be carefully considered so as to not affect your results (e.g., in an intervention study, providing this data after baseline data collection may impact participant's behavior in a control group). Acknowledgments, such as thank-you notes and birthday greetings, as well as small gifts such as water bottles and

drawstring bags with the study name and logo, can also be used to keep rapport and encourage retention once participants have commenced in your research (Arora et al. 2017b).

6.1.8 Reminders and Retention

Depending on the recruitment method, it may be possible to alert potential participants to a recruitment event. For example, if you plan to recruit through a workplace, then reminders on the run-up and day before the introduction of a recruitment stall may be appropriate. It is unlikely that you will have direct access to individual's contact details prior to recruitment for ethical reasons, but a third party might, who may be able to provide such reminders. With most adults owning mobile phones, a text or phone call reminder the day before launch of a recruitment strategy may be useful.

Just as for recruitment plans, plans for retaining participants also need to be tailored to the participant group. Retention can be helped by:

- Continued contact with participants (the various methods used needs recorded, as does the number of attempts and when). Using the same data collector can help build relationships with the participant.
- Planning a follow-up well in advance (alerting the participant to future visits or study involvement and thanking them after each involvement is key).
- Study branding provides participants with the opportunity to self-identify with the study (merchandise or study ID cards).
- Incentives and acknowledgments.
- Research team training (such as scripts to help with retention).

7 Recruitment of Older Adults

Recruitment and retention of older adults into research studies can be challenging, particularly for researchers engaging with clinical groups such as people with dementia (see also ► Chap. 114, “Researching with People with Dementia”). Accordingly, there are a number of recommendations and guidelines to facilitate working with older adults in a research context. For example, the NIH National Institute on Aging has developed the Recruiting Older Adults into Research (ROAR) Toolkit (National Institute of Ageing 2015), which contains a user guide, frequently asked questions, sample social media messages, and exemplar PowerPoint presentations and flyers to assist in helping seniors and carers learn why research participation is important, the benefits of research, and how to find opportunities.

As with other cohorts and age groups, the study design will play a large role in determining optimal recruitment strategies. One systematic review detailed that older adults' response rates to postal surveys could be increased by around half when participants were prenotified about the survey; using colored ink and offering an incentive also increased the response rate (Auster and Janda 2009). Another study testing a physical activity program for older adults effectively utilized a similar

approach by randomly identifying potential participants from the Australian Federal Electoral Roll, sending them postcards with information about the study to establish program credibility, and then calling them to invite them to join the project (Jancey et al. 2006). This strategy was found to be particularly cost-effective, with an estimated cost of \$30 AUD per recruit. Another Australian study found that direct mail-outs cost \$21 AUD per recruit, and this was more cost-effective and yielded a higher percentage of enrolments than oral presentations to community groups (\$21 AUD vs. \$144 AUD, 51.6% vs. 10%, respectively) (Clemson et al. 2004). However, other studies have found flyers to be the least effective method of recruitment when compared with referrals and face-to-face presentations (Adams et al. 1997). This suggests that fliers can be helpful if they are utilized as a priming mechanism to build trust and awareness in older adults before secondary contact is made by another means.

Face-to-face community-based recruitment strategies can be effective in facilitating grassroots engagement with research, particularly in tightly networked communities of older adults. One study found that the highest rate of face-to-face contact with older adults produced the greatest number of successful recruits (Ford et al. 2004). In our experience, we have found that involving organizations who have frequent touch-points with older adults including local councils (e.g., libraries, community centers, and leisure centers), seniors' clubs (e.g., RSL clubs, Probus, Lions Clubs, Rotary), and residential aged care facilities can dramatically facilitate recruitment, particularly if they have a dedicated liaison for seniors' outreach.

This level of grassroots engagement can produce referrals from friends and relatives, which have been shown to be one of the most effective methods of recruiting older adults into clinical trials (Adams et al. 1997). When recruiting for our mild cognitive impairment and dementia studies, our team asks our study participants to take a flyer and pass it on to a friend or relative. In addition, we ask carers (who attend study appointments with enrolled research participants) if they would like to be involved as a participant in control groups; they are often very willing to participate. Other referral strategies can come through networks of clinicians (e.g., primary care, staff specialists in hospitals or their private rooms, and community healthcare workers). This is a particularly effective method for recruiting clinical groups of older adults with specific eligibility criteria. A simple referral pathway that includes clear recruitment criteria, a site coordinator or recruitment champion, and incentives for referrals (e.g., access to clinical investigations, such as genetic testing or imaging, which would not otherwise be available, authorships on manuscripts, decreased workload) can facilitate recruitment of older adults via clinicians.

Other recruitment strategies for older adults can increase awareness of research studies (effectively priming) but may not yield recruits directly. This includes outreach such as newsletters or information on websites of advocacy groups (e.g., Dementia Australia, Australian Men's Shed Association, Older Women's Network NSW) and health governance organizations (e.g., Primary Health Networks, local health districts). Media outreach strategies (as detailed above) can also be an effective means of increasing engagement and awareness about research

participation opportunities for seniors. Other direct recruitment strategies include running classified advertisements in local newspapers, online campaigns (e.g., through social media; however, there are varying degrees of success here due to mixed levels of information literacy in older adults (Chesser et al. 2016)), and campaigns coordinated through clinical trial recruitment agencies (as detailed above).

8 Recruitment of Difficult-to-Reach Communities and Medically Compromised People

Hard-to-reach subgroups of the population will require additional recruitment planning. Such subgroups include vulnerable population groups such as children, pregnant women and newborn babies, prisoners, the homeless, terminally ill patients or those with life-threatening conditions, and cognitively impaired individuals (Liamputong 2007, 2013). Indigenous, culturally and linguistically diverse (CALD), refugee population groups are all disadvantaged communities that will also require extra consideration when planning recruitment. Many of these groups will be from low-socioeconomic status (SES) backgrounds, where often basic needs are of a higher priority than research involvement (Liamputong 2007, 2010).

In those with terminal disease or life-threatening conditions, there may be unforeseen circumstances (e.g., unplanned medical treatments) that arise unexpectedly and that will require extra flexibility from the research team (such as offering home visits) to ensure successful recruitment and retention. Eligibility criteria of this group may also change over time and will require consideration when calculating sample size estimates for studies. Timing of recruitment is a particularly important consideration for this population – although diagnosis may allow for longer follow-up from a research point of view, this can be a highly stressful time for the patient and therefore may not be an appropriate time for an invitation to participate in research. If recruitment at diagnosis is particularly important, then invitation from a healthcare professional may be more appropriate than researcher.

8.1 Community Ownership

When researching with hard-to-reach groups, working with the community from the inception of your research planning onward provides the opportunity to build community ownership of the research. Planning recruitment strategies with the feedback of the community is more likely to result in effective approaches. Empowering communities to undertake the research being conducted allows for trust to be developed; sustainability of the research relationship; better uptake, adherence, and involvement in research; and often research capacity building within community members. Providing community ownership is particularly important for indigenous groups where devolution of power has often led to distrust (Voyle and Simmons 1999). Guidance for undertaking research with indigenous populations exists (Henderson et al. 2002). In terms of recruitment, it is suggested that

partnership committees are developed and that consultation with the community is key around the research being proposed and the most appropriate methods and avenues for recruitment. Community committees can also supervise researchers throughout the recruitment process to ensure cultural appropriateness of implemented approaches. Where trust can be an issue initially, having a community champion or gatekeeper on board either from that community, whom already has an established and trusting relationship with the community, is vital for first introductions to a project and gaining access to that community. Employing or involving champions from the community to actually drive recruitment can also be beneficial or at least have cultural training of researchers who are involved in recruitment.

8.2 Incentives and Acknowledgments

Incentives may be particularly appealing for people of low socioeconomic status but should not be too big that they coerce individuals into participating. Learning about health or having access to health screening can in itself be an incentive for disadvantaged communities rather than the need for any monetary gifts. For example, diabetes health education and screening, prior to recruitment into a community-based diabetes risk reduction program, overcame barriers to participating in low socioeconomic communities from a range of minority backgrounds (Santoyo-Olsson et al. 2011).

8.3 Setting

Often, recruiting hard-to-reach groups through healthcare providers will not work, as visitation rates can be lower than for the general population. This may be due to a range of factors, including socioeconomic factors affecting access to healthcare; a lack of availability of health services; religious beliefs that “god dictates health” and, therefore, health is outside of the individual’s control; and a lack of trust or connection with healthcare providers (Simmons and Voyle 2003; Arora et al. 2018).

Extra work may be necessary to study the hard-to-reach target group to ensure an effective culturally appropriate recruitment strategy. This may mean adjusting intervention design and intervention and/or data collection settings, to take these out of conventional locations (such as universities and healthcare settings) and into communities. Recruitment of Maori people was effective in a study conducted in New Zealand where a diabetes prevention program was delivered via marae (the local community meeting grounds) (Simmons and Voyle 2003).

8.4 Several Means of Contact

Multiple recruitment strategies may be important for hard-to-reach groups to ensure that they actually receive invitation to a study, as often hard-to-reach groups are

highly mobile. It is recommended that multiple contact details are collected from such individuals, and this may need to include next of kin and friend's contact details too, in order to keep track of participants effectively. Rolling recruitment strategies may be necessary to allow enough time to sufficiently reach required sample sizes. Any materials used for recruitment will need to be culturally and linguistically tailored to the target group, to increase the chance of invitations being read.

In those with life-threatening illnesses, terminal disease attrition rates will be high, and it may be that others closely connected to the individual of interest are targeted to collect data from in this instance (e.g., proxy measures).

8.5 Recruitment of Medically Compromised Groups

Involving medically compromised (and often vulnerable) groups in research can be ethically and logistically challenging (Liamputtong 2007; McMurdo et al. 2011). There are guidelines available to assist with the ethical design and conduct of such research including the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council 2015), which details specific ethical considerations that need to be considered for certain groups of participants, for example, people highly dependent on medical care who may be unable to give consent (e.g., neonatal intensive care, terminal care, emergency care, intensive care, and the care of unconscious people) and people with a cognitive impairment, an intellectual disability, or mental illness. The consent process when recruiting medically compromised individuals for research involves careful consideration. The NHMRC guidelines recommend seeking consent from the individual wherever they are capable of providing consent, and it is practicable to do so. For people with a cognitive impairment or mental illness, their capacity to consent may fluctuate over time, and this needs to be taken into consideration. If it is not possible to obtain consent from an individual, it may need to be obtained from the participant's guardian (see also ► Chap. 106, "Ethics and Research with Indigenous Peoples").

In addition to some of the ethical issues outlined above, medically compromised populations can also be difficult to reach, making recruitment logistically challenging. Barriers to recruiting these populations include rare/low-prevalence populations; participants' willingness to participate and attitudes toward research, clinician characteristics, attitudes, and practices; perceived harms of studies; mistrust of research; low health literacy; and lack of time (Bonevski et al. 2014). There are a range of strategies that can be adopted to overcome these potential barriers to recruiting vulnerable and medically compromised groups (see Bonevski et al. 2014 for a comprehensive review). For example, to overcome the barrier of perceived harm of research, softer wording when describing the project can be utilized (e.g., "study" rather than "investigation," community-driven research in disadvantaged communities to overcome mistrust, using peer recruiters to overcome fear of authority).

9 Conclusion and Future Directions

To ensure successful recruitment and retention of suitable study participants, it is essential to consider the expectations and interests of both investigator and potential participants. It is vital that participants are best facilitated to ensure their utmost commitment toward the research and/or clinical trial, thereby lowering the risk of participant attrition, which can negatively impact research budgets and timelines. This chapter highlighted broad recruitment strategies to aid in effective design of the recruitment phase of research studies. Furthermore, detailed explanations of recruitment strategies across the life-span and in particular population groups have been provided.

Recruitment is very crucial for any research, and since research is continuously evolving and so are the health and social issues which tend to increase in future. Therefore, there is a strong need to carefully think about the effective recruitment methods of research participants in the planning stage of any research study. Furthermore, there might be additional innovative recruitment methods that researchers will invent in order to ensure that they can effectively recruit and retain research participants.

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Ontology and Epistemology

6

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Contents

1	Introduction	100
2	Ontology	101
3	Epistemology	102
4	Philosophy and Models of Human Functioning	104
4.1	The Biomedical Model: Naturalism and Objectivism	104
4.2	Biopsychosocial Model: Integrating the Psychological and Social with Biomedical	105
4.3	Critical Alternatives: Normativism and Subjectivism	106
5	Philosophical Positions, Methods, and the Quantitative Versus Qualitative Divide	108
5.1	A Brief Interlude About the Quantitative and Qualitative Divide	109
5.2	Philosophical Positions Inform Methodological Decisions	110
5.3	Methodological Decisions Inform Philosophical Positions	111
6	Conclusions and Future Directions	113
	References	114

Abstract

Health social science is an area of study wherein the methodological techniques used within the social sciences are applied to the investigation of human health. Methodological techniques, however, are not philosophically agnostic. Philosophical positions indeed matter in that they result in a range of individual

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and societal consequences. Consequently, it is important for students and researchers interested in studying the social aspects of health to understand the role of philosophical positions within research. Philosophical positions partly consist of ontological and epistemological assumptions. Ontological issues pertain to what exists, whereas epistemology focuses on the nature, limitations, and justification of human knowledge. This chapter introduces the reader to how ontological and epistemological positions are embedded within the biomedical, biopsychosocial, and critical alternative models of human functioning. Situating each of these models in relevant vignettes, we suggest that philosophical positions serve a dual role within inquiry in that they inform, and are in some circumstances informed by, the methodological and interpretative decisions enacted by researchers.

Keywords

Ontology · Epistemology · Methods · Biomedical · Biopsychosocial · Health Social Science

1 Introduction

Research is broadly framed from vantage points that partly consist of assumptions about the underlying nature of reality, how we understand that reality, and the kind of knowledge that may be obtained from observations and investigations of social phenomena. As such, social inquiry fails to be philosophically agnostic. Positions taken toward the nature of reality, or an object of investigation, are *ontological*, whereas stances toward the meaning and process of obtaining knowledge reflect what is *epistemological*. Together, ontological and epistemological positions, even when tacit, richly inform the arc of research in the health social sciences.

As an example, let us consider anorexia as a mental health phenomenon. A researcher who views anorexia as reducible to a physiological entity residing within a person draws from a different set of ontological assumptions than a researcher who views anorexia as the manifestation of socially constructed diagnostic criteria. Each view would not only result in different methodological decisions when investigating anorexia, but these perspectives also diverge in their diagnostic, treatment, and public policy implications (Lovett and Hood 2011). Students, investigators, and practitioners of the health social sciences therefore need to understand how philosophical positions (i.e., ontology and epistemology) shape, and to some extent are shaped by, the methodological and interpretative decisions enacted by researchers.

There are numerous obstacles to overcome if one desires to learn about the role of ontology and epistemology within social inquiry. Authors from various academic disciplines have contributed to a wide body of articles on the topic. Within this literature, the same term is often used in different ways or it may be completely ill-defined. For example, the term “paradigm” has been used in the literature to indicate an overarching worldview, epistemological stance, shared set of beliefs among specialists, and exemplar for how research is done in a particular area of study (Morgan 2007). There are also a seemingly endless number of philosophical stances

one may adopt; it likewise appears that new perspectives emerge frequently within the literature (e.g., Onwuegbuzie et al. 2009; Creswell and PlanoClark 2011; Denzin and Lincoln 2011; Houghton et al. 2012). In other words, there is much for a new reader to synthesize across numerous fields of study, which can seem like a daunting task.

Given these obstacles, one may question the value of taking the time to understand this line of literature. Without reflecting on such issues, one is like a ship at sea without a working navigational system. Without a navigational system – a compass, the stars, or a global positioning system – there is no awareness of direction, which could result in aimless wandering at sea. Within the context of research, ontological and epistemological considerations are our navigational systems, allowing us to become aware of our location, which in turn provides direction. We hope that, by the end of this chapter, the reader will come to appreciate the importance of navigating these considerations, as they invariably shape the direction of research studies.

We begin by discussing ontology and epistemology. This is followed by examining how these issues are connected to three models of human functioning that are frequently found within the literature. These models include the *biomedical model*, *biopsychosocial model*, and what we have labeled as *critical alternatives*. Then, we illustrate how philosophical stances serve a dual role within inquiry – to frame methodological decisions and in some circumstances to be informed by methodological and interpretative decisions. The concept of disease is used, for the purpose of illustration, for two reasons. First, the concept is highly controversial in medical discourse, which reflects differences in philosophical positions. Second, and perhaps more importantly, it seems to us that if these controversies exist in areas of research that many assume to be more certain, then how much more problematic might areas of research be that are assumed to be less certain, such as mental health and well-being? The controversies surrounding the concept of disease are applicable to mental health and well-being. With this said, examples drawn from mental health are interspersed throughout the chapter.

2 Ontology

We will begin by considering the topic of disease. What is a disease? Do diseases exist independently of our input as researchers? What conditions or states should be classified as a non-disease? These are complicated questions that have been a topic of debate among the readership of the *British Medical Journal (BMJ)* – one of the oldest peer-reviewed journals of medicine. Smith (2002) published an article based upon the results of a *BMJ* survey about the identification of non-diseases, which incited various debates about these concepts. From these debates, he concluded that not only is “...the notion of ‘disease’ a slippery one” but “health is equally impossible to define” (p. 883). Despite widespread disagreement about how to define a disease, a range of consequences may result from how healthcare professionals handle this concept (e.g., insurance reimbursement, treatment options, and so on). Though not explicitly addressed by the *BMJ*, these questions reflect ontological positions that have numerous implications within society.

Ontology is traditionally considered a branch of metaphysics aiming to describe the structure of reality (Poli 2010) or the study of being (e.g., Heidegger 1953). Historically, philosophical debates about ontology centered on the concept of realism. There are various versions of realism (e.g., Ladyman 2002); broadly speaking, a realist believes "...that entities exist independently of being perceived, or independently of our theories about them" (Phillips 1987, p. 205). Within the social sciences, a realist ontology is typically taken to mean that a phenomenon of investigation exists as an entity irrespective of our input as researchers (Hood 2013; see also ► Chap. 9, "Positivism and Realism"). For our purposes, we will delineate the realist from an anti-realist, defined here as the rejection of the view that a phenomenon of interest exists independently of our input as researchers.

Consider once again a disease. An ontological realist would hold that diseases are in fact "things in the world" that exist irrespective of our input as researchers. This view was illustrated by Thomas Sydenham, a mid-seventeenth-century physician, who provided an account of the history of diseases in his *Observationes Medicae* (1676). Sydenham claimed "...that diseases were distinct entities, possessing natural histories, and emphasized how disease was independent of the sufferer" (Low 1999, p. 259). Conversely, an anti-realist would reject the notion that disease exists independently in favor of a cultural construction such as this, "Each civilization defines its own disease. What is sickness in one might be a chromosomal abnormality, crime, holiness, or sin in another" (Illich 1976, p. 112). Such ontological positions are related to how one would investigate disease, the kind of knowledge believed to be obtained via such investigations, and the strategies employed to justify knowledge claims (i.e., epistemology).

3 Epistemology

Epistemology is a branch of philosophy that examines the nature, limitations, and justification of knowledge (Williams 2001). What is knowledge? What is the relationship between the knower and the known? How are knowledge claims justified? The scope of epistemology is fairly broad given that there is a range of positions to consider for each of these questions. At the risk of oversimplification, we draw upon the framework provided by Crotty (1998), which outlines three epistemic positions: (1) objectivism, (2) constructionism, and (3) subjectivism. Before discussing each view, it is first necessary to make a distinction between a phenomenon and the meaning of a phenomenon (Biesta 2010).

When asked, most people likely believe that world stuff – the material of which our universe is made of, like "matter" – would continue to exist if people ceased to exist (i.e., phenomenon). In other words, most would argue that the world does not disappear simply because no one is present to observe it. However, does this world have meaning? In order for world stuff to be meaningful, an observer must interpret such meaning (i.e., the meaning attributed to phenomenon). Consider a person who has been diagnosed with HIV/AIDS. There may be specific entities that exist irrespective of the diagnosis, but what it means to be diagnosed with HIV/AIDS

could be culturally constructed. For example, the entities that compose a virus (i.e., phenomena) may exist irrespective of a diagnosis, but whether HIV/AIDS is conceived as a punishment from God, act of witchcraft or product of evolution may be culturally constructed, thus indicating that phenomena can be distinguished from meaning given to phenomena. The three general epistemic positions outlined by Crotty (1998) pertain to the meaning of phenomena.

Having established the distinction between phenomenon and the meaning of a phenomenon, an objectivist, constructionist, and subjectivist have different views toward the relationship between the knower and the known. An *objectivist* “holds that meaning, and therefore meaningful reality, exists as such a part from the operation of any consciousness” (Crotty 1998, p. 8). In other words, “diseaseness” has meaning irrespective of our interpretations, and it is an aim of science to discover this meaning. Cultural constructions of disease, under this view, may be more or less aligned with objective meaning. How we come to find meaning is rooted in positivist/postpositivist assumptions that phenomena can be understood through deductive methods, experimental approaches, and robust statistical methodologies (see also ► Chap. 9, “Positivism and Realism”).

The *constructionist*, on the other hand, views meaning as coming “into existence in and out of our engagement with the realities of our world. There is no meaning without a mind. Meaning is not discovered, but constructed” (Crotty 1998, pp. 8–9). The constructionist does not necessarily deny the existence of a mind-independent world but instead contends that the meaning of this world is culturally, socially, historically, and politically situated. Under this view, the mind interacts with world stuff to derive the meaning of disease. Further, the constructionist upholds the possibility of multiple, coexisting meanings. To this end, methodologies associated with constructionism are often qualitative (e.g., phenomenology, grounded theory, narrative inquiry) with analyses reflecting inductive techniques (Gale and Dolbin-MacNab 2014; Hathcoat and Nicholas 2014; Nicholas and Hathcoat 2014; see also ► Chap. 7, “Social Constructionism”).

Finally, the *subjectivist* upholds the notion that experience, and thus meaning, is independent of a fixed reality. In other words, meaning is firmly situated in culture, social interaction, and so forth. As mentioned by Crotty (1998), it is tempting under this view to state that there are no boundaries set by a mind-independent world to limit the creation of meaning. A subjectivist might, therefore, claim that the concepts of a disease and non-disease reflect but one of many possible ways to categorize, label, and impose order on the human condition. Methodologically, a subjectivist “tends toward participatory action research (PAR) approaches where the purpose of the research, analysis, and results is to involve the communities being studied and achieve emancipatory change” (Gale and Dolbin-MacNab 2014, p. 250; see also ► Chap. 17, “Community-Based Participatory Action Research”).

Ontological and epistemological stances could be combined in different ways. We suggest, however, that not any combination of ontological and/or epistemological positions is reasonable. For example, it seems misaligned to combine ontological realism with subjectivism within a single study. In our opinion, it is probably wise to avoid seemingly contradictory ontological and/or epistemological stances within a

single study. Addressing each of these complexities, however, extends well beyond the aim of our chapter, so we will refer to ontological and epistemological positions more generally as philosophical perspectives.

4 Philosophy and Models of Human Functioning

Three models are prominent within the literature when describing human functioning. These models include (1) biomedical, (2) biopsychosocial, and (3) critical alternatives. Each of these models has been informed by distinct philosophical positions and has resulted in numerous societal consequences. The biomedical model of human functioning is the oldest and most criticized yet deemed in many respects as one of the most successful for treating “physical” ailments. However, this perspective resulted in a tendency to neglect the psychological, social, and cultural aspects of human functioning that led to the biopsychosocial model. Both of these models, however, have been critiqued by scholars in the social sciences for heavily relying upon a realist ontology. For the sake of simplicity, we have labeled the third model as “critical alternatives,” recognizing that such criticisms have resulted from authors with various views toward human functioning.

4.1 The Biomedical Model: Naturalism and Objectivism

The biomedical model of human functioning became prominent in the mid-nineteenth century among health professionals who sought to apply the methods of science to the diagnosis and treatment of disease. This model “. . . is characterized by a reductionist approach that attributes illness to a single cause located within the body and that considers disturbances of mental processes as a separate and unrelated set of problems” (Wade and Halligan 2017). Medical practice, which had been intertwined with religious ideology (Koenig 2000), started to rely upon the empirical methods of science to explain human functioning. No longer were such ailments conceived as the result of “supernatural” forces, but technological developments led to the view that diseases were instead the result of microbial organisms that attacked the body, a perspective that came to be known as the germ theory of disease (Smith 2012).

The biomedical model is consistent with the concept of naturalism, defined here as the “general view that the concept of disease reflects an objective reality about cell, organ, or system function or dysfunction” (Sisti and Caplan 2017, p. 7). This view derived from the dualistic depiction of the mind and body advocated by Descartes (Longino 1998) in which humans are conceived as an “ensouled machine” (Sisti and Caplan 2017, p. 6). The mind (nonphysical) is considered distinct from the body (physical), and diseases are located within the body. The biomedical model is, therefore, consistent with a realist ontology and an objectivist epistemology. Said differently, diseases are mind-independent entities that can be correctly classified,

diagnosed, and treated. The methods of science consequently aim to predict, control, and explain human functioning.

Under the biomedical model, the application of statistical and experimental methods resulted in numerous advancements throughout the nineteenth and early twentieth centuries. Under a naturalist view, it is important to have a sense of typical or “normal” functioning in order to identify a disease, which is once again defined as a bodily dysfunction. How would one identify dysfunction without first knowing something about typical functioning? Statistics is a tool that one may employ to investigate typical patterns of a population, thus making it a viable strategy to investigate dysfunction. In fact, the employment of statistical techniques to investigate population risk factors became the basis of epidemiological research (Berkman and Kawachi 2000; see also ► Chap. 33, “Epidemiology”).

Experimental methods were also used to develop vaccinations throughout the nineteenth and twentieth centuries, which resulted in preventing widespread outbreaks of infectious disease (Hsu 2013). Moreover, by the end of World War II, the double-blind, randomized control trial became the “gold standard” of medical research (White and Willis 2002; see also ► Chap. 37, “Randomized Controlled Trials”). This is evident by the fact that in 1962 the US Congress passed an act that supported the use of randomized control trials to demonstrate the quality of a drug prior to approval and by 1970 such trials were mandated by the Food and Drug Administration (Bothwell and Podolsky 2016). In other words, throughout much of the nineteenth and twentieth century, the biomedical model not only dominated the conceptualization of human functioning among healthcare professionals but also resulted in numerous benefits to society.

4.2 Biopsychosocial Model: Integrating the Psychological and Social with Biomedical

There were numerous challenges to the biomedical model that stemmed from its inability to integrate the psychological and social aspects of human health and disease (Engel 1977). For example, stress, social support, and other related variables appear to be important factors in the progression of particular forms of cancer and heart-related issues (e.g., Valtorta et al. 2016). These challenges imply that there are aspects of human functioning that fail to be captured by physiological, genetic, and/or other forms of organic dysfunction. Said differently, human health is more than the absence of such characteristics, a view captured the World Health Organization (1948/2014, p. 1) when stating, “health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” Such criticisms eventually led to the biopsychosocial model of human functioning.

The biopsychosocial model “. . . holds to the idea that biological, psychological, and social processes are integrally interactively involved in physical health and illness” (Suls and Rothman 2004, p. 119). This challenged the Cartesian, mind-body dualism embedded in the biomedical model. The idea that a disease is either of the mind (i.e., psychosomatic) or strictly physical is problematic given that “most

psychosomatic diseases involve varied genetic and environmental determinants, and all states of health and disease are influenced to some extent by psychosocial conditions” (Berkman and Kawachi 2000, p. 4). In other words, the psychological, social, and physical intersect in a myriad of ways to contribute to human functioning.

The biopsychosocial model is perhaps best characterized as an expansion of the biomedical worldview (Wade and Halligan 2017). The biopsychosocial model does not deny the existence of physical determinants of health and disease. For example, consider the case of deafness as a biological dysfunction. Is this a disease? Under a biopsychosocial model, biological dysfunction is necessary but not sufficient to count as a disease given that a disease must include social harm (Sisti and Caplan 2017). In other words, an individual who is deaf may have a high state of well-being, thus making it questionable whether biological dysfunction alone is sufficient to be labeled as a disease (Hausman 2017). This example leads us to a range of philosophical and practical consequences.

The biopsychosocial model may be viewed as a hybrid between ontological realism and constructionism. In other words, “. . . we might invoke pluralistic realism – which allows for both the recognition of biologically real entities and pragmatic usages of differing definitions to meet particular needs” (Sisti and Caplan 2017, p. 17). The concept of disease consequently becomes a target that “. . . changes with time, depends on practice, and influences medical taxonomy” (Hoffman 2017, p. 23). In other words, there are parameters that to some extent set limits as to what could be reasonably be considered health, disease, and well-being though how each is conceived within these parameters is in many respects socially and culturally affected.

The biopsychosocial model has resulted in numerous positive consequences when compared to the biomedical model. For example, Veatch (2006, p. 589) indicated that in the 1970s, “physicians were being asked to use surgical techniques to control human behavior by destroying portions of the brain believed to be responsible for criminal and violent behavior.” Such practices derive from a biomedical model and its evident ontological and epistemological foundations. The biopsychosocial model, while adhering to a scientific worldview, has led to a person-centered approach toward treatment (Wade and Halligan 2017). Therein, treatment should focus on the whole person as opposed to simply aiming to rid an individual of biological dysfunction. With this said, the biopsychosocial model of human functioning is consistent with the application of methodological techniques that aim to understand human experience (e.g., phenomenology) in conjunction with strategies that are used to assess statistical deviations from typical functioning.

4.3 Critical Alternatives: Normativism and Subjectivism

Various movements within the philosophy of science advanced criticisms that extend well beyond those raised by advocates of the biopsychosocial model. The extent to which scientific progress could be viewed as the rational accumulation of knowledge became suspect (e.g., Kuhn 1962/2012). Scientific progress, it seemed, was more

disorderly, haphazard, and socially influenced than previously believed. Other challenges arose from the fact that it seemed impossible to isolate hypotheses to be tested in isolation (e.g., Quine 1953). Instead of testing hypothesis “X” in isolation, such as within an experiment, we are simultaneously testing an interrelated network of assumptions about measurement, theory, sampling, and so on. Finally, the idea that empirical observations could be separated from theoretical and value-laden presuppositions came under scrutiny (e.g., Fleck 1935/1979). Such criticisms incited various researchers within the social sciences to abandon objectivist sympathies. Scientific knowledge was instead viewed by many critics as just one of many forms of knowledge.

With respect to human health, diagnosis, and treatment, it was possible to identify historical cases in which so-called diseases or disorders served as a source of oppression. Most of these examples stemmed from behavioral or mental health conditions though in many respects a “mental health disorder” has often been viewed similarly to a disease (e.g., mental health disorders can be viewed as a biological dysfunction or the result of intersecting biological, psychological, and social conditions). Such cases include delinquency, dissidence, homosexuality, and masturbation (Hoffman 2017). For example, Englehardt (1974, p. 234) concluded the following when discussing the “disease” of masturbation:

Masturbation in the 18th and especially in the 19th century was widely...held to be a dangerous disease entity. Explanation of this phenomenon entails a basic reexamination of the concept of disease. It presupposes that one think of disease neither as an objective entity in the world nor as a concept that admits of a single universal definition: there need not, nor need there be, one concept of disease.

Masturbation was used by Englehardt to argue that values are inextricably connected with notions of dysfunction. Other commonly cited examples include a social scientist who in 1851 argued that runaway slaves suffered from a disease called drapetomania and the view that “uncivilized” people were immune to mental health problems since psychiatric issues were characterized as a maladaptive reaction to “civilization” (e.g., Whitley 2015). In other words, historically situated, moral ideologies came to be viewed by such scholars as responsible for shaping what was considered dysfunctional (e.g., Foucault 1961/1989).

These positions toward human functioning are characterized by normativism and a tendency toward epistemological subjectivism. Normativist theories view health and disease as primarily value-driven thus “...when we signify something as a disease, we are marking out something that is subjectively disvalued by society, culture, or individual preferences” (Sisti and Caplan 2017, p. 9). Masturbation was a disease because it was disvalued by the moral ideology of a particular society. An objectivist may argue that although masturbation was at one time believed to be a disease, this view was simply mistaken. In other words, the people at this period of time were incorrect. The subjectivist, on the other hand, does not view this issue so simply. For example, what criteria determine that masturbation is no longer a disease aside from a shift in cultural values? Might other so-called dysfunctions be similarly

disregarded in the future because they are driven by oppressive ideologies? The subjectivist may conclude that such examples illustrate how the categories of disease and non-disease are cultural creations that in many respects both frame and limit the human condition.

What we have labeled as critical alternative views have not been widely adopted by the healthcare profession, perhaps because it is unclear how the profession would engage in diagnosis and treatment under these perspectives. Researchers adopting a critical alternative view tend to deconstruct how society shapes our concepts of dysfunction, health, and well-being. For example, many researchers have raised concerns about an increasing tendency to “medicalize” human behavior. Take attention-deficit hyperactivity (ADHD) as an example. To what extent is this disorder a function of how society has structured education? It seems that “many children with this diagnosis do not feel ill [although]...social norms for education and conduct make them sick” (Hoffman 2017, p. 20). In other words, a critical alternative view might opine that children are educated in artificially constructed environments governed by strict social norms. The subjectivist may argue that a failure to adhere to the norms that govern an artificial environment makes otherwise functional behavior appear dysfunctional (e.g., Armstrong 1999).

Nevertheless, important questions remain unanswered. What would a healthcare profession look like that adopted these philosophical positions? Might treatment reflect the philosophy of Paulo Freire (1970/2014) who, in the *Pedagogy of the Oppressed*, discussed an educational strategy in which one aims to have individuals regain their humanity through liberation? Asked differently, would the medical profession serve to “liberate” as opposed to “diagnose” individuals? Though we do not have answers to such questions, the critical alternative views sketched in this section have at least resulted in a growing awareness among the academic community of a tendency to medicalize (perhaps unwarrantedly) numerous aspects of the human condition (e.g., Veatch 2006; Murray 2014).

5 Philosophical Positions, Methods, and the Quantitative Versus Qualitative Divide

Thus far, we have argued that philosophical positions indeed matter. Different models of human functioning are informed by specific assumptions about the nature of reality, how we understand that reality, and the kind of knowledge believed to be obtained via inquiry. Each of these models also tends to result in numerous consequences with respect to how we conceptualize, diagnose, and treat human functioning within society. Within this section, we further illustrate that such positions indeed matter by addressing the relationship between philosophical stances and methodological decisions. We argue that philosophical stances serve a dual role within inquiry. Philosophical stances can inform methodological decisions; however, methodological decisions may also be more or less consistent with particular philosophical stances. In other words, philosophical stances inform, and are in some sense informed by, methodological decisions enacted by researchers. However, prior to addressing this issue, it is

first necessary to clarify terminology given that there is contention within the social science literature about the nature of quantitative and qualitative inquiry.

5.1 A Brief Interlude About the Quantitative and Qualitative Divide

As previously stated, numerous movements occurred in academia throughout the 1960s and 1970s. These movements were partly informed by criticisms that were gaining traction within the philosophy of science. The picture of science as objective or value-neutral became increasingly suspect, and numerous researchers within the social sciences and education reacted to such criticisms by questioning what was viewed as the dominance of quantitative research. Perhaps the most vehement arguments for this perspective derived from Guba and Lincoln (1994) who described quantitative methods as largely deriving from particular philosophical positions that stood in contrast to alternative worldviews that informed qualitative inquiry (Lincoln and Guba 1985). Under this view, ontological positions form the foundation upon which epistemic stances emerged, which subsequently constrained methodological decisions of researchers. For example, a realist ontology was said to inform a view of knowledge that was objectivist which in turn leads to specific methods (i.e., experimental design), whereas anti-realist views may lead to methods that aim to reconstruct the meaning of an experience.

This work sets the stage for questions about the commensurability of quantitative and qualitative methods within a single study (Howe 1988; Guba and Lincoln 2005). Though largely anecdotal, we have also found that it has become increasingly common to hear individuals identify themselves as either a qualitative or quantitative researcher. However, these terms may be more misleading than helpful (see Morgan 2007; Sandelowski 2014). For example, what does it mean to be a qualitative or quantitative researcher? Is all quantitative research united by a common philosophical stance? Is there something wrong with a qualitative researcher collecting numerical data?

Although space prohibits us from addressing all of these controversies, the presence of such issues demonstrates a need to clarify terminology prior to addressing the relationship between philosophical positions and methodological decisions. Instead of referring to qualitative research or quantitative research, we will instead employ the terms quantitative and qualitative to refer to *data* (Biesta 2010). In other words, quantitative will be used to indicate numerical data, whereas qualitative will be used to indicate forms of data that are non-numerical such as texts, images, artifacts, and so on. The term *method* refers to the techniques, strategies, or procedures used to investigate a question of interest. Semi-structured interviews, focus groups, and surveys are examples of methods used to investigate questions of interest. We also remind the reader that *philosophical positions* are defined as the ontological and epistemological stances that are either explicitly or implicitly adopted within an investigation.

The distinction between data, methods, and philosophical stances allows us to draw attention to specific aspects of the relationship between philosophical stances and methodological decisions. Consider a possible relationship between philosophical

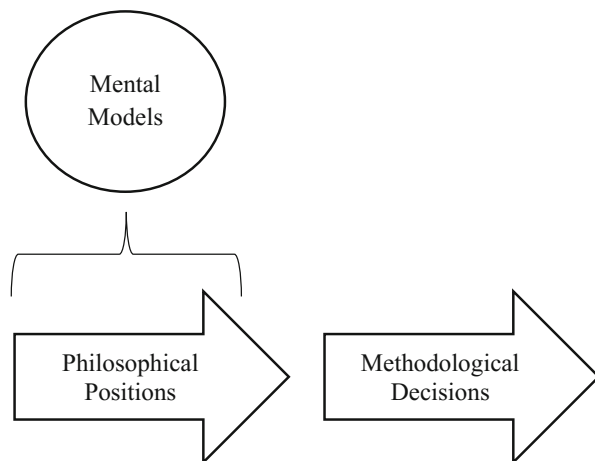
stances and data. It seems counterintuitive to claim that specific epistemic stances inform the type of data that may be used in an investigation. There is nothing blatantly problematic with a subjectivist using numerical data as part of their investigation just as there is nothing problematic about an objectivist analyzing texts. Consequently, the following section focuses on the relationship between philosophical stances and methodological decisions as opposed to the kind of data that results from such decisions.

5.2 Philosophical Positions Inform Methodological Decisions

If asked, many researchers may not be able to explicitly state their ontological and epistemological positions when investigating a phenomenon. However, further probing is likely to detect their underlying philosophical assumptions. Researchers approach inquiry from a mental model. Mental models consist of “the particular constellation of assumptions, theoretical commitments, experiences, and values through which a social inquirer conducts his or her work” (Greene 2007, p. 3). Philosophical positions, though often implicit, are aspects of mental models that inform inquiry. This is similar to the position advanced by Guba and Lincoln (1994) in that it is a top-down approach, which is depicted in Fig. 1.

Figure 1 indicates that mental models are partly comprised of philosophical positions (i.e., ontology and epistemology) that in turn shape methodological decisions. Mental models are broader than philosophical positions. For example, particular commitments to social justice or theory are conceptually distinct from ontological and epistemological positions. However, under this view, philosophical positions, whether implicit or explicit, inform methodological decisions. Although we have alluded to this relationship when discussing different models of human functioning, we will discuss how this would work using a hypothetical example drawn from Lovett and Hood (2014) who discuss ADHD and the concept of malingering.

Fig. 1 Mental models consist of philosophical positions that inform methodological decisions



The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, indicates that an individual must exhibit multiple symptoms, such as failing to give close attention to detail and frequently fidgeting, to receive a diagnosis of ADHD. This diagnosis is often assessed by using a variety of rating scales in which scores are given for items referring to the occurrence of such symptoms. In this scenario, malingering would occur if an individual without the disorder was motivated to present false symptoms in order to obtain the diagnosis (Suhrs et al. 2008). How would researchers with distinct philosophical stances understand the rating scale scores, the concept of ADHD, and malingering?

As indicated by Lovett and Hood (2014), ontological assumptions influence how we handle this scenario. The ontological realist would view ADHD as an entity that is independent from how we choose to operationalize the concept. When combined with an objectivist epistemology, the rating scale scores either successfully refer or fail to refer to an individual with ADHD. Malingering is compatible with this philosophical stance since it implies that some people identified as ADHD have intentionally misled the examiner. Said differently, under a realist ontology and objectivist epistemology, the scores on the rating scale allow us to say something about whether an individual possesses a real entity. Malingering is a potential concern since it suggests that we may be led to the wrong conclusion about this diagnosis.

The situation becomes more complicated when we turn to other philosophical stances. For example, the constructionist tends to adhere to ontological realism and epistemic relativism (Crotty 1998). In other words, in this case there may be a real, mind-independent entity underlying the diagnosis, but the meaning of ADHD socially created. The constructionist may, therefore, view the ADHD criteria as set of socially negotiated and/or culturally defined concepts. When viewed in this way, there may be a common underlying experience whose meaning is constructed by individuals meeting the diagnostic criteria, though given epistemic relativism it is conceivable for other, equally legitimate constructions, to emerge. The rating scale scores could potentially be used to help us understand how individuals position themselves within such constructions. It is unclear, however, how to handle the concept of malingering from this perspective due to its reliance on the concepts of truth and falsehood. Malingering no longer consists of a discrepancy between reality and professed symptoms but may instead be viewed as a form of coherence between self and societal constructions. In other words, under this view, an individual may present the self as more or less aligned with how society has conceived of ADHD while recognizing this alignment may change given new, equally legitimate, societal constructions. Notice how in this case the collection of quantitative and qualitative data is irrelevant since the rating scale scores could presumably be interpreted differently under distinct philosophical stances.

5.3 Methodological Decisions Inform Philosophical Positions

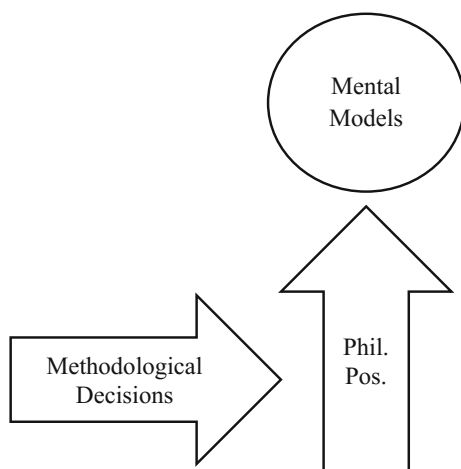
The position that mental models, which partly consist of philosophical stances, inform methodological decisions is relatively uncontroversial. However, alternatives

to this perspective, in which methodological decisions can also inform philosophical positions, have been advanced (e.g., Hathcoat and Meixner 2017). To conceptualize an alternative view, one may ask questions about the direction of the arrows in Fig. 1. Is it conceivable for the arrows to run in the other direction? Do methodological decisions frame the philosophical stances that are more or less reasonable to adopt irrespective of whether this is explicitly recognized by the researcher? It seems that the answer to this question is yes, at least under certain circumstances. Such an alternative is briefly sketched in this section since it is fairly controversial and the primary aim of this chapter is to introduce the reader to the topics of ontology and epistemology within social research.

Figure 2 illustrates a possible relationship between mental models, philosophical stances, and methodological decisions under an alternative perspective. According to Fig. 2, methodological decisions can in some sense inform philosophical positions that in turn lead to mental models. Some methodological decisions are, relatively speaking, “philosophically neutral” since they can be consistently employed from numerous philosophical perspectives. Semi-structured interviews and focus groups are examples of strategies that are relatively neutral since they can be applied by researchers who adopt objectivist, constructionist, or subjectivist epistemologies (see also ► Chap. 23, “Qualitative Interviewing”). Researchers adopting distinct epistemic stances would differ in how they interpret the results (e.g., an objectivist would attempt to code the data in an effort to identify the true themes), but the methods themselves do not seem to lead to any problems with a researcher who wishes to adopt one of the three epistemic stances.

Problems do seem to emerge in other situations. Consider the double-blind control trials we previously mentioned when discussing the biomedical model of human functioning. In such trials research participants are randomly assigned to either an experimental group that receives a new treatment or a control condition in which participants either receive no treatment, a placebo, or some standard treatment (see ► Chap. 37, “Randomized Controlled Trials”). Individuals administering the

Fig. 2 Methodological decisions inform philosophical positions that in turn inform mental models



treatment are unaware of which participants are assigned to each condition. Might such methods have philosophical implications, irrespective of whether or not they are recognized by the investigators? For example, asking whether *X* causes *Y* seems to make implicit assumptions about realism. How could something nonexistent act as a cause? Other examples include the idea of parameter estimation in statistics. The concept of estimation seems difficult to defend without accepting some form of realism since there must be something to estimate for the concept to make sense (Hood 2013; see ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)).

We do not wish to imply that a realist must use experimental methods since causal questions may be investigated using alternative methodologies (e.g., Maxwell 2004). Nor do we wish to suggest that everyone who employs an experimental design must accept specific philosophical stances. Instead, there may be a range of stances that are coherent with aspects of this methodology, though some stances may be more problematic than others given apparent contradictions. In sum, under an alternative model, it is naïve to assume that methodological decisions occur in a philosophical vacuum. Failing to consider the philosophical aspects of methodological decisions may at best lead to ambiguity, lack of transparency, and/or confusion. At worst, failing to attend to the philosophical aspects of methodological decisions leads to interpretations that are altogether unwarranted, misleading, and/or incoherent.

6 Conclusions and Future Directions

When writing this chapter, we discussed with friends, family, and colleagues the controversies surrounding the concept of disease within medical discourse. Within these conversations some would ask, “Why does it matter how we conceptualize a disease?” To be candid, this question came as a surprise, which may partly be due to the fact that we were immersed within this line of literature. But, how could it *not* be important? The concept of a disease is connected to philosophical positions, resulting in a range of practical consequences for both the individual and society. In other words, the importance of ontology and epistemology was obvious to us, but it was not necessarily transparent to other people. We hope that by the end of the chapter, readers will share our sense of surprise by this question.

Ontological and epistemological considerations extend well beyond “armchair” philosophical debates. Philosophical stances indeed matter. Throughout this chapter, we have used the concept of a disease, interspersed with examples from mental health, to illustrate how ontological and epistemological considerations are embedded within models of human functioning. We have also described how philosophical stances serve a dual role within inquiry. Ontological and epistemological considerations frame social inquiry in that they provide a lens through which we investigate and interpret phenomena. Lastly, we sketched the possibility that methodological decisions can in some sense inform philosophical stances since methods themselves are often laden with ontological and/or epistemological assumptions. Nevertheless, a couple delimitations or caveats are worth mentioning.

Numerous researchers have created typologies of philosophical stances and/or theoretical perspectives such as postpositivism, pragmatism, and critical realism (e.g., Weaver and Olson 2006; Creswell 2009; Onwuegbuzie et al. 2009; Moon and Blackman 2014). We have tried to avoid creating another typology. Admittedly, we have drawn upon the work of Crotty (1998) in order to provide an overview of three epistemic positions; however, we do not want the reader to assume that these are the only positions that exist. Thus, the picture we have presented, which is also a feature of typologies, runs the risk of being overly simplistic. A second danger of typologies is that it can reinforce the position that researchers must choose between fixed, preexisting categories which fail to recognize the inherently constructed aspect of these views. Typologies also fail to consider the nuances and debates that exist within each category. With this caveat in place, the picture presented in this chapter aims to provide a useful entry point to a line of literature for the reader.

We have also not explicitly addressed other topics that are related to the philosophical stances discussed in this chapter. For example, there are debates about the aim of inquiry, which is often viewed as the idiographic and nomothetic distinction (see Robinson 2011). Is generalization possible? Are there universal laws of human functioning? What about the role of values within inquiry? There are also conceptual distinctions between health and well-being that are worth exploring (Hausman 2017). For the sake of clarity, we set such issues aside though we encourage the reader to pursue these topics as they continue to grapple with the role of ontology and epistemology within social inquiry.

In closing, we return to the metaphor of a ship being at sea without a navigational system. All too often, coursework focuses on methodology without regard for how philosophical positions provide a navigational system through which to understand social inquiry. In other words, methods are often presented as though they occur within a philosophical vacuum. This can result in aimless wandering at sea without a sense of location. Despite the obstacles to understanding this line of literature, as scholars and professors, we believe that ontological and epistemological considerations are too important to remain ignorant about. We do not expect a new reader to have figured out their navigational system by the end of the chapter. However, we do believe that at this juncture a new reader should recognize how philosophical stances can serve to navigate the vast sea of health social science research.

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Social Constructionism

7

Viv Burr

Contents

1	Introduction	118
2	Origins and Influences	118
3	What Is Social Constructionism?	120
3.1	A Critical Stance Toward Taken-for-Granted Knowledge	120
3.2	Historical and Cultural Specificity	121
3.3	Knowledge, Social Processes, and Social Action Are Related	121
4	How Does Social Constructionism Challenge Mainstream Psychology?	122
4.1	Essentialism	122
4.2	Language as Representation	124
4.3	Objectivity and Universalism	124
4.4	Power and Politics	125
5	Illness: A Constructionist Illustrative Example	126
6	Social Constructionist Research	127
6.1	Foucauldian/Critical Discourse Analysis	128
6.2	Discursive Psychology	129
7	Conclusion and Future Directions	130
	References	131

Abstract

Social constructionism emerged in social psychology in the 1970s and 1980s, taking up many of the issues raised as part of the earlier “crisis” in social psychology and becoming a critical voice challenging the agenda of mainstream psychology. In particular, it challenged psychology’s individualistic, essentialist, and intrapsychic model of the person, replacing it with a radically social account of personhood in which language is key. Viewed through the constructionist lens,

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the person ceases to be a unified ensemble of stable psychological structures and traits and becomes a fluid, fractured, and changeable assemblage, distributed across and produced through social interactions and relationships. Social constructionism's critical focus has meant that its research agenda is also radically different from that of mainstream psychology and social psychology. Social constructionist research rejects the mainstream psychological experimental paradigm and turned attention to the constructive force of language and discourse, opening up new lines of research and developments in a number of methods referred to as discourse analysis.

Keywords

Social constructionism · Discourse analysis · Critical psychology · Power relations · Crisis in social psychology

1 Introduction

Social constructionism represents a radical challenge to mainstream psychology in both theory and research. It began to emerge in social psychology in the 1970s and 1980s as a recognizable body of work by those who would, today, refer to themselves as, for example, “critical psychologists” and “discursive psychologists.” Social constructionism poses a challenge to psychology's individualistic, essentialist, and intrapsychic model of the person, replacing it with a radically social account personhood and is, therefore, essentially a social psychology. The taken-for-granted topics of mainstream psychology and social psychology, such as attitudes, motivation, personality, and emotion, were brought into question as structural features of the human psyche and instead seen as social constructions achieved through social interaction and language. As Craib (1997) points out, many social constructionist assumptions are fundamental to psychology's disciplinary cousin, sociology, and it is a measure of the unhelpful separation of sociology and psychology since the early twentieth century that psychologists have only recently begun to engage with social constructionist ideas.

2 Origins and Influences

Although social constructionism is a relatively new term in the social sciences, especially psychology, its ideas and practices have a longer history in disciplines such as sociology, philosophy, and linguistics. The key tenet of social constructionism is that our knowledge of the world, including our understanding of human beings, is a product of human thought, language, and interaction rather than grounded in an observable and definable external reality. Such an idea, although strange to many psychologists, is fundamental to longstanding concepts in the sociology of knowledge, such as ideology and false

consciousness, which focus on how sociocultural forces construct our knowledge in particular ways.

An important contributor to social constructionist thinking has been the micro-sociological approach of symbolic interactionism (see Berger and Luckmann 1966). George Mead, at the University of Chicago, had developed this approach from the earlier work of Herbert Blumer and later published his ideas in *Mind, Self and Society* (1934). Mead had studied at Leipzig University under Wilhelm Wundt, who believed in the importance of sociocultural factors, such as myth, folk customs, and religion, in understanding human behavior and experience. Mead took up these ideas in his development of symbolic interactionism, which argues that people construct and negotiate identities for themselves and others through their everyday social interactions with each other. Language, as a system of socially shared symbolic meanings, is central to this constructive process. In line with this, the sociological subdiscipline of ethnomethodology, which grew up in North America in the 1950s and 1960s, aimed to research the processes by which ordinary people construct social life and make sense of it to themselves and each other, and ethnomethodology has been one of the influences on social constructionist research (see also ► Chaps. 10, “Symbolic Interactionism as a Methodological Framework,” and ► 16, “Ethnomethodology”).

Berger and Luckmann argue that human beings together create and then sustain all social phenomena through social practices. They argue that although our world is socially constructed through the interactions of people, it is at the same time experienced by them as if the nature of their world is pre-given and fixed; we are all born into a social world that preexists us and that, therefore, seems “natural.”

In addition to these North American influences, social constructionism has also drawn on the ideas of more recent European thinkers. The historian and philosopher Michel Foucault has been highly influential, as has Ferdinand de Saussure in structural linguistics and the work of the philosopher Jacques Derrida on “deconstruction.” The ideas of these writers have been extensively drawn upon in developing social constructionist thinking around the role of language in the construction of human social phenomena.

In psychology, the emergence of social constructionism is usually dated from Gergen’s (1973) paper *Social Psychology as History* in which he argues that all knowledge, including psychological knowledge, is historically and culturally specific; we, therefore, must look beyond the individual and enquire into social, political, and economic realms for a proper understanding of the evolution of present-day psychology and social life. He argues that it is pointless to look for final descriptions of people or society, since the only abiding feature of psychological and social life is that it is continually changing. Social psychology, thus, becomes a form of historical undertaking, since all we can ever do is to try to understand and account for how the world and people appear to be at the present time.

Gergen’s paper was written at the time of what is referred to as “the crisis in social psychology” (see, e.g., Harré and Secord 1972; Armistead 1974), which provided some of the momentum for social constructionist ideas in psychology. This crisis centered on worries about the way that social psychology’s agenda was driven by the

needs and motivations of powerful factions (government, the military, and commerce); social psychology as a discipline can be said to have emerged from the attempts by psychologists to provide the US and British governments during the Second World War with knowledge that could be used for propaganda and to manipulate behavior. Social psychology, therefore, had historically served, and was paid for by, those in positions of power, both in government and in industry. Its theories and research findings often seemed to bring further oppression to relatively powerless and marginalized groups (women, ethnic minorities, working class people, and those of nonnormative sexual orientation), and this operated partly through the study of human phenomena in socially decontextualized laboratory environments, since experiments ignored the real-world contexts which, it was argued, give human conduct its meaning. There was a move to attend to this social context, as well as to explore human phenomena from the perspective of psychology's "subjects" themselves rather than privilege the perspective and voice of the relatively powerful researcher. These concerns encouraged social psychologists to embrace the ideas already flourishing in neighboring disciplines, including micro-sociology, and also fed into the burgeoning call to recognize qualitative research methods as legitimate and fruitful for the discipline of psychology.

3 What Is Social Constructionism?

One of the earliest writers to describe social constructionism was Kenneth Gergen, and in his 1985 publication *The Social Constructionist Movement in Modern Psychology*, he laid out what he saw as its key features, which today remain useful orienting principles.

3.1 A Critical Stance Toward Taken-for-Granted Knowledge

Social constructionism takes a critical stance toward psychology's taken-for-granted ways of understanding the world and ourselves. Psychology has modeled itself on the natural sciences. These assume the epistemological approach of positivism, the view that knowledge comes from objective, unbiased observation of the world and that there is a true or accurate description of people, events, and things that science endeavors to reveal. Positivism assumes that the world comes to us ready-made, and our task is to discover its true nature. Within this epistemology, the experiment is the gold-standard research paradigm (see ► [Chaps. 6, "Ontology and Epistemology,"](#) and ► [9, "Positivism and Realism"](#)).

But social constructionism cautions us to be suspicious of our assumptions about how the world appears to be. For example, it may seem obvious to us that there are two naturally occurring categories of human being, men and women. But social constructionism bids us to seriously question whether the categories "man" and "woman" are simply a reflection of distinct types of human being and to consider instead that they are categories constructed by people themselves in the course of

social interaction. When we consider the many individuals whose sex cannot easily be decided on the basis of their anatomy, and the increasingly prevalent phenomena of transgender and gender reassignment surgery, we can begin to appreciate that being a man or a woman is much more socially negotiated than we might have imagined. The same is true of other highly socially relevant concepts, such as “race.” While in former times, it may have seemed unquestionable that there exist different races of human beings, each with its own physical and psychological characteristics, research has failed to find any genetic basis for such distinctions; while human beings come in a diverse range of shapes, sizes, and colors, there is no evidence for the existence of genetically discrete races (see, e.g., Yudell et al. 2016).

We may ask why this matters and what social significance it has. The social constructionist would argue that challenging the existence of such natural categories helps us to disrupt and destabilize many of the assumptions we hold about men and women and about nonwhite peoples, assumptions that underpin inequitable practices. The familiar arguments that particular characteristics (or lack of them) are natural for women or men, or for black people, are frequently used to defend inequalities.

3.2 Historical and Cultural Specificity

The agenda of mainstream psychology is to discover universal principles of psychological functioning or “human nature.” But social constructionism argues that the ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific and depend upon where and when in the world one lives. For example, concepts of illness and disease have changed significantly over time and vary across different cultures. What we believe illness and disease to be are fluid products of our culture and history rather than fixed entities (see below). This means that we cannot assume that *our* ways of understanding are necessarily any better, in terms of being any nearer the truth, than other ways. Indeed, the concept of “truth” itself becomes problematic. Looking at knowledge this way challenges the idea of scientific progress, the idea that through science we are advancing toward a more and more accurate understanding of the physical and psychological world. Social constructionists argue that this way of thinking has led to the imposition of our own systems of knowledge upon other cultures and nations; psychology has been accused of being imperialist in its attitude toward other cultures and has colonized them, replacing their indigenous ways of thinking with Western ideas.

3.3 Knowledge, Social Processes, and Social Action Are Related

Social constructionism argues that our knowledge is not derived from the nature of the world as it “really” is; rather, people construct it between them through their daily interactions. This is why social interaction and language are of great interest to social

constructionists, since it is in the course of these practices that our shared versions of knowledge are constructed. For example, what we know and understand as dyslexia is a phenomenon that has come into being through the exchanges between those who have difficulties with reading and writing, their families and friends, and others who may teach them or offer them diagnostic tests. Knowledge is, therefore, seen not as something that a person has or does not have, and is neither correct nor incorrect, but is something that people create and enact together.

Our social interactions are capable of producing a variety of possible social constructions of events. What we regard as knowledge is, therefore, one possible construction among many. But different constructions invite different kinds of action or practice from us. For example, before the growth of the Temperance movement in nineteenth-century USA and Britain, people under the influence of alcohol were seen as entirely responsible for their behavior. Therefore, punishment, such as imprisonment, was seen as an appropriate response. However, the Temperance movement represented alcohol itself, and addiction to it, as the problem. Today, addiction of various kinds, whether to drugs or to behaviors such as gambling, is constructed as a kind of illness and the alcoholic is, therefore, seen as not totally responsible for their behavior. The social action appropriate to understanding drunkenness in this way is to offer medical and psychological therapy not punishment. Constructions of the world, therefore, sustain some patterns of social action and exclude others.

4 How Does Social Constructionism Challenge Mainstream Psychology?

The three key social constructionist arguments outlined above challenge some of the equally key features of mainstream psychology and social psychology: essentialism, language as representation, and objectivity and universalism. Social constructionism also attends to power and politics, issues on which psychology has arguably been silent.

4.1 Essentialism

The model of the person at the heart of mainstream psychology represents the person as pre-existing society and social life. It has an “essence” consisting of characteristics or qualities that make it what it is, and this essence may have been produced by genes or by the influence of the environment (or a mixture of both). The social constructionist argument for cultural and historical specificity is sometimes mistakenly interpreted as just another way of taking the nurture side in the nature/nurture debate. But social constructionism is not just saying that one’s cultural surroundings have an impact upon one’s psychology or even that our nature is a product of environmental, including social, rather than biological factors. Both of these views are essentialist, in that they see the person as having some definable and discoverable nature, whether given by biology or by the environment, and the agenda of psychology is its discovery. Psychology has, therefore, produced a number of different

theories to account for this essence, such as personality trait and type theories, which in turn give rise to instruments designed to measure personality, such as the popular Myers-Briggs Type Indicator (1943/1976), and psychodynamic theories.

The content of this individual is described by the various and competing psychological theories: personality traits and intelligence, unconscious motivations and drives, learned behaviors and habits, attitudes, and beliefs. All of these constructs are similar, however, in that they are thought of as properties of the person, whether inherent or acquired environmentally, and they are held to cause or determine our behavior. Social constructionism regards all such concepts as constructions, and like any other constructions, they have arisen in the course of social life in particular sociocultural conditions. Social constructionism is anti-essentialist and also, therefore, challenges the psychology's determinism; we cannot appeal to psychological essences to explain behavior. By contrast, social constructionism rejects the idea that the person consists of a unified and stable collection of features or characteristics. Instead, the person is viewed as fractured and distributed across social relationships; we are "produced" on a myriad of different occasions and, in different ways, dependent upon the nature of the social situation in which we find ourselves. There is, therefore, no essential "self" that describes who the person "really" is.

Psychology's essentialism often takes a reductionist form. Reductionism is the practice of describing a complex phenomenon in terms of simpler or more fundamental elements. Psychology has tended to assume that all behavior will eventually be explained in terms of biological mechanisms, and the complex social and cultural conditions that inform psychological phenomena are likewise reduced to biological causes. For example, we often encounter the idea that social inequalities and differences between women and men derive from psychological sex differences which are themselves the result of differences in hormone levels or brain structure that are said to have evolutionary origins. Developments in neuroscience have arguably led psychology even further in this reductionist direction. Neurological accounts of experience and behavior are becoming commonplace in everyday discourse, and according to Cromby (2012), we are increasingly invited to understand our experiences in terms of brain chemistry rather than social relations.

The significance of social constructionism's challenge here is that essentialism is regarded as potentially trapping people inside personalities and identities that may be restrictive and pathologizing for them, rendering psychology an oppressive practice. For example, if someone is described as psychotic and this is seen as an abiding feature of their personality, they not only face a future in which change appears unlikely but may also become subject to invasive psychiatric procedures. Essentialism also creates a tendency for psychologists to seek dispositional explanations for human behavior and to look for causes of behavior in psychological states and structures rather than in social processes. A person may be diagnosed with depression, but their depression may be constructed either as part of their personality or as a consequence of their poor living conditions; one construction leads to drug treatment and the other to improvements in housing and so on.

4.2 Language as Representation

The implicit model of language within psychology is as a vehicle for representing external or internal realities, and our representations may be accurate or inaccurate and truthful or dishonest. The accuracy and truthfulness of our linguistic accounts have assumed importance in our understanding of memory, with applications in areas such as eyewitness testimony. Memories are only one example of psychological entities that are thought to be expressed through language. Others, often captured through both quantitative and qualitative research methods, include attitudes, emotions, and subjective experience.

The position of social constructionism on the status of internal psychological conditions is not always straightforward. Some constructionists prefer to “bracket off” psychological states, much as behaviorists did in the early twentieth century; because we can have no direct access to psychological states and have only a person’s verbal reports of them, behaviorists claimed that psychologists should only concern themselves with what is observable, i.e., behavior. Likewise, many social constructionists do not concern themselves with language as a representation of inner psychological states. But this is because their interest is in an important aspect of language that they feel has been ignored by psychology and that is its constructive force.

Social constructionism argues that language has practical consequences for people that should be acknowledged. For example, when a doctor declares that a person is suffering from schizophrenia, and “sections” them under the Mental Health Act, this has immediate and significant consequences for the person’s freedom. It is this constructive and “performative” function of language that is of principal interest to social constructionists. It is through our discourse with each other that people are constructed as mentally ill, as masculine or feminine, and as old or as disabled, and social constructionists are interested in how and why people become constructed in the way that they do, whether through our active discourse with each other, through the small-scale linguistic turns of individual social interactions, or through the myriad linguistic and symbolic representations or “discourses” that abound in our cultural life. As I will discuss later, this focus on language leads to a radically different research agenda from that pursued by mainstream psychology.

4.3 Objectivity and Universalism

The social constructionist critique of mainstream psychology centers upon reminding psychology that its own grasp on the world is necessarily partial. It is partial both in the sense of being only one way of seeing the world among many potential ways and in the sense of reflecting vested interests.

Within the mainstream research paradigm of science, which psychology adopts, the researcher can claim truthfulness for their findings by recourse to the supposed objectivity of scientific method. The experimenter is represented as able to stand back from their own humanity and reveal the objective nature of the phenomena

under study without bias and without contaminating the results with “leakage” from their own personal involvement. This vision of and value for objectivity is part of the philosophical position of realism. Realism assumes a singular and objectively describable world. It asserts that an external world exists independently of our representations of it (see also ► [Chap. 9, “Positivism and Realism”](#)).

Psychology has also adopted from the natural sciences the assumption that there are universal laws governing the behavior of all things (including people) and that these laws can be discovered through experimental research. For example, the widely used Health Belief Model (Rosenstock 1966) describes a model of health decision-making that is assumed to explain how all people make behavioral choices, regardless of their cultural or historical location.

Within social constructionism, all knowledge is derived from looking at the world from some perspective or other and is in the service of some interests rather than others. This means that there can never be objective facts, things that are simply true for all people regardless of their time and place. Relativism, in contrast to realism, argues that the only things we have access to are our various perceptions and representations of the world, and these cannot be judged against some assumed reality for their truthfulness or accuracy. Relativists, therefore, cannot prefer one account to another on the basis of its apparent truthfulness. The dangers in insisting that there is only one truthful and, therefore, acceptable way of understanding the world and its people are arguably being played out in political arenas both internationally and more locally in issues such as religious fundamentalism, gay rights, and sexual harassment. Different constructions can only be compared in terms of their usefulness, their potential for benefitting people.

But psychology’s vision of the world and people is also partial in the sense of coming from a particular cultural perspective and is, therefore, not objective. The discipline of psychology, like other academic disciplines, has been dominated by the work and interests of white, middle-class men, and this has inevitably shaped the knowledge that their work has produced. The concept of intelligence was arguably constructed by them in their own image, and it is only in relatively recent times that this has been challenged. For example, the introduction of the notion of “emotional intelligence” is an attempt to value aspects of psychological functioning that are not captured by the cognitive reasoning focus of IQ tests.

Although the tenets of social constructionism appear to lead automatically to a relativist position, some writers, often referred to as critical realists, prefer to retain some concept of a reality existing outside of our constructions of it while accepting the view that there are multiple, competing perspectives on events that are bound up with power relations (e.g., Cromby and Nightingale 1999; see also ► [Chap. 9, “Positivism and Realism”](#)).

4.4 Power and Politics

Psychology has traditionally regarded itself as apolitical; its search for the objective facts about people seems to place it outside of the political arena. However, if we

take the social constructionist view that psychology is partial and that objectivity is a fiction, it is possible to regard the discipline as instrumental in the maintenance of inequality and oppression. Through its status as a science, psychology has presented as truth representations of people that serve to legitimate inequalities. For example, through “sex differences” research, psychology has promoted the popular idea that women and men are different kinds of people and, therefore, suited to different roles in society; through its measurement and testing program and through its diagnostic classification system, it has set norms for intelligence, personality, and behavior based on white, male middle-class norms and values and has pathologized people whose behavior and experience lie outside of these prescriptions.

It is a concern with such matters that is the principle focus of critical psychology and critical social psychology (see, e.g., Fox et al. 2009; Gough et al. 2013). Critical psychologists focus on issues of exploitation and oppression and social justice. A key development has been in “postcolonial” critical psychology (see Hook 2012), which aims to problematize the discourses that help to maintain and legitimate disadvantaged Third World countries. Social constructionism and critical psychology do not, however, map onto each other directly; although much critical psychology can be said to be social constructionist in spirit, some critical psychologists would not necessarily refer to themselves as social constructionists.

Another strand to the social constructionist concern with power derives from the work of Michel Foucault. Foucault argues that the way people talk and think about, for example, sexuality and mental illness, the way these are widely represented in society, brings implications for the way we treat people. Our representations entail particular kinds of power relations. For example, we think of people who hear voices as mentally ill and refer them to psychiatrists and psychologists who then have power over many aspects of their lives. Foucault refers to such representations as “discourses,” since he sees them as constituted by and operating through language and other symbolic systems. Our ways of talking about and representing the world through written texts, pictures, and images all constitute the discourses through which we experience the world.

5 Illness: A Constructionist Illustrative Example

In order to illustrate these social constructionist principles, I will use the case of “illness.” The social construction of illness has now become a major perspective in medical sociology (Conrad and Barker 2010). It is generally assumed that illness is a biological matter that can be objectively determined, in line with what is termed the biomedical model of illness. However, it is by no means easy to make a judgment about whether or not a person is ill. This is because illness is not simply a biological matter – it is a social one. When we say that we or someone else is ill, we are making a judgment that only in part relates to their physical condition. Much of our judgment rests on cultural prescriptions, norms, and values surrounding our ability to perform our usual activities and upon power relations. Bury (1986) cites the work of Figlio (1982), who studied the relationship of the condition miners’ nystagmus to social

class and capitalism. The existence of this as a disease entity was not simply a medical matter – it was at the center of conflicts over malingering and compensation for workers. As Burr and Butt (2000) have noted, in recent times, we have seen the emergence of a number of conditions that were unknown in earlier times, for example, premenstrual syndrome and ME (myalgic encephalomyelitis), and the medical status of these is similarly problematic and infused with cultural assumptions and moral prescriptions.

In addition, it seems that the biomedical model is one that is not universal and is a fairly recent development. Medical belief systems in other cultures are often radically different from biomedicine, and in our own society, we are seeing an increasing use of alternative medicines which are often based upon belief systems quite different to biomedicine, such as homeopathy, acupuncture, and reflexology. Social constructionism argues against the view that our own predominant, biomedical view of disease is the right one and all others false. All medical belief systems operate within a culture with norms, values, and expectations that make sense of illness for people in that culture and set the criteria for what, locally, can count as illness.

The variation in ways of understanding illness that exists across cultures and across the range of alternative medicines in our own society can also be seen historically. Radley (1994) describes how, up until the end of the eighteenth century, doctors saw the patient's emotional and spiritual life as directly relevant to their state of health. With developments in the study of anatomy, it became possible to think of illnesses as things attacking the body as a system of interrelated organs, with the result that the experience of the person as a whole became irrelevant to diagnosis.

But the rise of biomedicine is not something that can be seen as simply a story of the progress of medical knowledge. It is a way of viewing the body that, it can be argued, is intimately connected to broader social developments. The study of the inner workings of the body in the anatomy laboratory took place in the context of a more general movement toward understanding the world by ordering and classifying it. Foucault (1973, 1976, 1979) has argued that such ordering and classifying, with respect to human beings, has played a key role in controlling the populace. By classifying people as normal or abnormal, mad or sane, and healthy or sick, it became possible to control society by regulating work, domestic, and political behaviors. For example, the certified mentally ill may not vote and may be forcibly confined, those who cannot obtain a sick note from their doctor may have no choice but to work and those whose parenting is seen as inadequate may be separated from their children.

6 Social Constructionist Research

It will be clear that the aim of social constructionist enquiry must leave behind psychology's questions about the nature of people and, instead, turn attention to a study of the emergence of current forms of psychological and social life and to the social practices by which they are created. Social constructionism asks how certain phenomena or forms of knowledge are constructed through language, either through

the way people are positioned within wider cultural discourses or through their everyday social interaction. Research conducted from within the first of these approaches is often concerned with identifying the ideological and power effects of discourse and is referred to as Foucauldian or “critical” discourse analysis (see also ► [Chap. 50, “Critical Discourse/Discourse Analysis”](#)). Research focusing on the constructive work of individuals during social interaction is often referred to as discursive psychology. Confusingly, both kinds of research may be referred to as simply “discourse analysis,” although much work within discursive psychology in the UK has now moved toward the adoption of conversation analysis (CA) as a research method and often uses this term instead (see also ► [Chap. 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”](#)). However, Foucauldian and discursive psychological approaches to social constructionist research should not be seen as mutually exclusive; Wetherell (1998) argues that they are not in principle incompatible and that we could and should attend to both situated language use and the wider social context within which these are produced.

It would be a mistake to suggest that there are particular research methods that are intrinsically social constructionist; social constructionist research simply makes different assumptions about its aims and about the nature and status of the data collected. However, the insistence of social constructionism upon the importance of the social meaning of accounts and other texts often leads logically to the use of qualitative methods as the research tools of choice (see ► [Chap. 63, “Mind Maps in Qualitative Research”](#)). In practice, this has often been the analysis of interview transcripts, recordings of naturally occurring conversations, newspaper articles, and other texts of various kinds.

6.1 Foucauldian/Critical Discourse Analysis

The Foucauldian strand of social constructionism acknowledges the constructive power of language but sees this as bound up with material or social structures, social relations, and institutionalized practices. The concept of power is, therefore, at its heart. The principle form it takes today is critical discourse analysis (CDA), which is particularly associated with the work of Norman Fairclough in the UK (Fairclough 1995). Since their focus is on issues of power, these researchers are especially interested in analyzing various forms of social inequality, such as gender, ethnicity, disability, and mental health, with a view to challenging these through research and practice. The way that discourses construct our perceptions and experience can be examined by “deconstructing” texts, taking them apart and showing how they work to present us with a particular vision of the world and of ourselves and thus enabling us to challenge it (see also ► [Chap. 50, “Critical Discourse/Discourse Analysis”](#)).

Foucauldian discourse analysis aims to identify the discourses operating in a particular area of life and to examine the implications for subjectivity, practice, and power relations that these have. The kinds of materials that may be used in such an analysis are virtually limitless; any text or artifact that carries symbolic meaning may

be analyzed. So, to the extent that such things as family photographs, choices of interior décor, hairstyles, or road signs carry meanings that may be “read” by people, they may be analyzed. In the illustrative example below, Conradie (2011) used CDA to analyze a men’s lifestyle magazine, *For Him Magazine (FHM)*. He asks what role such publications might have in disseminating and perpetuating gendered expectations. Conradie analyzed written articles from the magazine, examining these for the assumptions and values that appeared to be underlying these texts and for how women and men were represented within them. Some of the extracts from the magazine used by Conradie are shown below:

Extract 56: ‘Lady-pleasuring, like wiring up a stereo, requires reading the instruction book ...’.

Extract 57: ‘Learn to read the telltale physical give-aways of her body’s arousal’.

Extract 58: ‘A few minutes of rub and tug [massage] and she’ll be putty in your hands’.

Extract 59: ‘It might sound cheesy, but dimming the lights, playing ambient tunes and lighting a candle or two will get your lady ready for rubbing [massage]’.

Extract 60: ‘Good massage will lead directly to full sex. Guaranteed’.

Extract 61: ‘It’s willingness over technique here, but it will pay off’.

Firstly, Conradie notes that the articles focused on men’s sexual performance, representing sex as a skill that men should master and suggesting that successful sex depends on gaining the correct knowledge and following certain rules (e.g., Extract 56). Conradie argues that this supports an ideology in which sex is about the successful expression of masculinity. He also notes that there is no mention of any emotional or relational context of sex. Instead, it endorses a hedonistic (male) lifestyle where sexual liaisons with multiple women are accepted as the norm and women are constructed as the recipients of actions performed by the reader (“you”). Conradie concludes that *FHM* aims to encourage a hedonistic lifestyle, with relationships with women constructed as opportunities for the display of men’s sexual prowess.

6.2 Discursive Psychology

The focus on social interaction and language as a form of social action introduced above has been placed center stage by discursive psychology (e.g., Edwards and Potter 1992). Discursive psychology shares the radically anti-essentialist view of the person of social constructionism, and in particular it denies that language is a representation of internal states or cognitions such as attitudes, beliefs, emotions, and memories. Its concern is to study how people use language in their everyday interactions, their discourse with each other, and how they put their linguistic skills to use in building specific accounts of events, accounts which may have powerful implications for the interactants. It is, therefore, primarily concerned with the performative functions of language.

The action orientation of discursive psychology, therefore, transforms mainstream psychology’s concern with the nature of phenomena into a concern with

how these are *performed* by people. Thus, memory, emotion, and other psychological phenomena become things we do rather than things we have. Discursive psychology focuses mainly on the analysis of social interactions in order to reveal the rhetorical devices that people use to construct persuasive accounts and achieve their interactional goals. The example below, taken from Dick (2013), is a brief illustrative example. Dick undertook a discursive analysis of interviews with UK policewomen about sexism in the workplace. In the following extract, “Sophie” is describing her reaction to some postcards on the wall of a CID office, showing women in scanty bikinis:

1. *S:* But I remember thinking, ‘This is a professional office!
2. I’ve never seen naughty post cards in a professional office before’.
3. And I was foolish enough in retrospect to say, ‘My Goodness me!
4. What are those doing on the wall? That’s a bit off isn’t it?’
5. Having pictures like that in a CID office?’
6. Cos y’know, you wouldn’t walk into a solicitors’
7. and see that, or most places. I mean
8. I equated that kind of calendar girl
9. stuff with garages!
10. *Me:* Absolutely! That’s where I would have expected to see them!

Dick points out that Sophie has to work hard to bring off an account that persuades the hearer that sexism is objectively real. She heads off any possible suggestion that her reaction to the postcards is due to her being “prudish” or oversensitive and, therefore, prone to making accusations of sexism; she begins her account (lines 1–2) by casting the postcards as only problematic due to their location in a CID office. In lines 3–4, she frames her reaction as naïve, an example of what discursive psychologists call stake inoculation; this framing allows her to further protect herself from any claim that she might be oversensitive by constructing herself as an ordinary person who was simply perplexed by what she saw. Sophie further builds the credibility of her account in lines 5–9, introducing the idea that such a display in a public office suggests a lack of professionalism. She also uses another rhetorical device, an extreme case formulation (“or most places”, line 7), to suggest that such a display is significant because it is very unusual, and in lines 8–9, she extends her initial point by comparing professional locations (like a CID office) with garages, where she would expect to see such material.

7 Conclusion and Future Directions

Social constructionist theory brings with it a reformulation of what it means to do social science research. The concepts that are the cornerstones of traditional psychology, such as objectivity and value freedom, are radically questioned. Within social constructionism, there exist approaches to research that vary in the kinds of materials they typically analyze and the conceptual tools they use to perform their analysis. A notable difference between them is the extent to which they are

concerned with the workings of language beyond the confines of the text under analysis. Despite these differences, what they share is an understanding of language as performative and constructive, and this is what differentiates them from mainstream psychology.

Despite the rising popularity of social constructionism, there appears to have been little take-up of its ideas by the mainstream discipline. Academics continue to research and write principally within one paradigm or the other, many mainstream journals continue to favor work carried out within a traditional, positivist framework, and the agendas of the two paradigms continue to lead more or less parallel, self-contained lives.

As we are arguably living in a more and more globalized society, it may be argued that we need to see the adoption of a generally social constructionist perspective in our world view. It is no longer viable to attempt to live our lives according to our own very local “truths.” In particular, we need to recognize the dangers inherent in prevailing essentialist, Western concepts of the person. The biomedical model of illness has already been successfully challenged in the field of disability, in the now widespread popularity of the “social model of disability” (Makin 1995; Hughes and Paterson 1997), which frames disability as a product of social structures and power relations rather than a quality of the disabled individual. It may be argued that similar conceptual developments are needed to help us properly understand and address other social problems. Burr and Butt (2000) argue that the proliferation of previously unknown psychological conditions that has occurred in recent decades should be seen as a socially constructed phenomenon, and the continuing rise in “mental illness” is arguably not best conceptualized through an ultimately stigmatizing, essentialist and individualist disease model.

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Critical Theory: Epistemological Content and Method

8

Anastasia Marinopoulou

Contents

1	Introduction	134
2	The Epistemological Content of Critical Theory	136
3	The Method of Critical Theory	140
4	Critical Theory's Task: The Normative Turn	143
5	Conclusions and Future Directions	147
	References	148

Abstract

Critical theory situates science within the quest for social and political rationality. It indicates that science's normativity – which answers the question “what should science do?” – orients itself in relation to the a priori potential of society. The latter for critical theory transforms itself into concrete political vindications for science. Adorno's *Gesamttgesehen*, which differentiates from any total and, therefore, totalitarian conception of what science is, along with Horkheimer's dialectical approach to science through interdisciplinarity and Habermas' notion of communicative rationality (that emphasizes scientific dialogue) in science, finds themselves in marked contrast to the rest of modern epistemology. The chapter traces the epistemology of critical theory of the Frankfurt School through the twentieth and the twenty-first centuries via the concepts of dialectics, critique, reason, interdisciplinarity, communicative action and rationality, and their social

Some parts of the chapter are based on previous elaborations in my *Critical Theory and Epistemology: the Politics of Modern Thought and Science* (Manchester University Press, 2017). I owe particular thanks to Professor Darrow Schecter and Professor Piet Strydom for all the inspiring discussions, comments, and critique which encouraged me to reconsider many things.

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and political function and role within modernity. The main aims of twenty-first-century epistemology of critical theory become as follows: formulate a theory of normative rationality, reclaim commitments to rational praxis, and educate the sciences to maintain dialectics as their pivotal scope and method of advance.

Keywords

Critical theory · Dialectics · Political epistemology · Normativity

1 Introduction

Critical theory situates science within the quest for social and political rationality. It indicated that science's normativity – which answers the question “what should science do?” – orients itself in relation to the a priori potential of society. The latter for critical theory transforms itself into concrete political vindications for science. Adorno's *Gesamtgesehen*, which differentiates from any total and, therefore, totalitarian conception of what science is, along with Horkheimer's dialectical approach to science through interdisciplinarity and Habermas' notion of communicative rationality (that emphasizes scientific dialogue) in science, finds themselves in marked contrast to the rest of modern epistemology (Adorno 1970; Adorno et al. 1976; Horkheimer 1988a, 1995; Habermas 1988, 2006) (For a critical account and comparison see my *Critical Theory and Epistemology: The Politics of Modern Thought and Science*).

This chapter traces the epistemology of critical theory of the Frankfurt School through the twentieth and the twenty-first centuries via the concepts of dialectics, critique, reason, interdisciplinarity, communicative action and rationality, and their social and political function and role within modernity (Habermas 1987). My aim is to answer the question “how is science evaluated?” or “who is science accountable to?”. Fundamentally, I trace which questions critical theory should ask in order to measure the accountability of science and which answers it attempts to provide.

For critical theory of the twentieth century, the concept of dialectics appears significant both for society and science and marks both the first generation of Horkheimer, Adorno, and Marcuse with their critique of science, its social and political task, and the potential for interdisciplinarity and the second generation of Habermas with science's potential for public dialogue through communicative action (Marinopoulou 2008). Moreover, the chapter's arguments focus on the idea of dialectics as both a process *and* a method. Therefore, both following subchapters elaborate on the dialectical process and dialectical method, respectively. By questioning what *form of process dialectics* is, epistemology realizes that dialectical arguments are formed without losing sight of what occurs in social and political reality. For the latter reason, epistemology cannot avoid having a political character; science is socially produced and carries social and political implications. Dialectics is also *a method* because it derives from the exchange of argumentation between scientific subjects. Since dialectics has social consequences, it needs *accountability criteria* in order to be socially acceptable. Dialectics is accountable to society *because* it brings with it certain

political consequences. Along the way, it also renders epistemology a scientific field that discusses the political character of scientific development.

The main aims of twenty-first-century epistemology of critical theory become as follows: formulate a theory of normative rationality, reclaim commitments to rational praxis, and educate the sciences to maintain dialectics as their pivotal scope and method of advance. Such epistemological aims would probably also advance epistemology toward realizing its political potential to influence society. As in the social and political sphere, where consensus of all participants appears important but not a condition *sine qua non*, the same is also valid for the sciences. It is not consensus that necessarily marks a creative scientific process; rather, it is dissensus that sciences have to promote through dialogue.

In the twenty-first century, critical theory has to prioritize dialogue that would reclaim as a process the lost honor of science, namely, to form knowledge that is accountable to society. Therefore, through dialogue the task of critical theory is to form a political epistemology. Dialogue within and about scientific arguments serves to contradict and expose mythical and dogmatic thinking. It also has the capacity to purge orthodox or absolute convictions of any arbitrary meaning. In such a manner, we come closer to understanding what constitutes the scientific sphere, philosophy, and truth and whether modern epistemology paves the way for a political epistemology in the twenty-first century. Science is neither dogma, religion, nor politics. Its basic function should be to provide a forum for open and uncoerced dialogue wherever a point of dispute arises. Science is neither a fixed understanding nor a vague assumption, but a scientific moment occurs when a question or a negation is formulated and asserted.

Critical theory's epistemological arguments are marshaled in a vehement critique of positivism (Adorno et al. 1976; Schecter 2010, 2013; Stockman 1983), which marks its claims as a reaction against rational normativity or as the new empiricist epistemology safeguarding scientific orthodoxy. By rejecting all subjective understanding according to consciousness and by prioritizing the empirical data (but what sort of empirical data? according to which criteria? the ones of time, space, historicity, or of the human senses?) as objects of knowledge, positivism questions the significance of dialectics for cognitive processes and resorts to causal explanations for its epistemological method and aims (see also ► Chaps. 6, "Ontology and Epistemology," and ► 9, "Positivism and Realism").

In an intriguing interview (<http://www.youtube.com/watch?v=KyP6li6AnE0>), Horkheimer states that philosophy can no longer be considered progressive because it is in the service of science, thus, distorting the task of philosophy, as well as that of science. The constant problematic, which I examine as either implicit or explicit in epistemology, is whether scientists are falling silent over what takes place in science or in the political or social sphere. It appears that philosophy has to incorporate the concerns of an epistemology orientated toward the political, the political significance of scientific research and arguments, and focus on an epistemology with a political perspective, namely, on a political epistemology. As was often the case in human history, particularly with the Newtonian scientific discoveries that pave if not open the way for the French Enlightenment, science serves as the bearer of multiple innovative changes first in the domain of research and then in society and politics.

Thus, far from any elitist approach to what science or philosophy is, philosophy has to function as the accountability bearer and evaluator of science in its relationship with society. It is neither degrading nor reductionist to consider philosophy so philosophy *among its other tasks* can and should promote political epistemology. The latter consideration entails a social and political elevation for philosophy within modernity that attributes to philosophy the normative task of social accountability regarding what science is and ought to be.

Later in the twentieth century, Horkheimer's argument found a similar elaboration in one of Marcuse's statements on science (https://www.youtube.com/watch?v=C5PU0EASi_Q). Marcuse argues that there is certainly a part of philosophy, science, and technology, which is neutral (Marcuse 1968). Nevertheless, due to its social position, science takes a firm ideological stand. Science and philosophy, by questioning what is true and valid, do not merely fill the void left by dogmatism and mythology which stretch into the realms of society and politics by creating prejudice and suppression; they set dialectics and dialogue itself at the center of their process. The negation in dialectics has to be followed by something else, too, and that can be the enlightenment of the negation, not necessarily in the form of a synthesis with the thesis but by arguments on the potential, the "other," and the alternative, both in science and society.

The ongoing innovations of modernity in science and society lay the foundation not only for an innovative science but also – and not consequently – for the promise of social progress and development. In order to understand what is modern, we probably have to affiliate it with what is scientific and to question what is dialectical. If I were to draw a hypothetical line between what is scientific and modern and separate them from the prescientific and premodern, that line would be dialectics itself.

2 The Epistemological Content of Critical Theory

The following analysis of the three major thinkers of the Frankfurt School aims to approach the basic *questions* that the first generation of the Frankfurt School expressed and attempted to answer, particularly in relation to epistemology and the social and political potential of the sciences. The first generation of critical theorists includes Max Horkheimer, Theodor W. Adorno, and Herbert Marcuse and deals extensively with the concept of dialectics in science and the potential for an interdisciplinary approach to what the scientific and the political are. The same idea of a dialectical science would be advanced by Jürgen Habermas, the leading figure of the second generation of critical theorists, with his concept of communicative action which relates to a great extent to the concepts of dialectics and the interdisciplinarity of the first generation.

For Horkheimer, Adorno, and Marcuse, there exists a recurrent epistemological concern, namely, that science contributes to the freedom of humans from social prejudices and political irrationality during modernity as well as to the formation of rationality for society. Nevertheless, science steadily transmutes rationality into irrational methodology, method, purpose, and a ruthless domination of humans

over nature that culminates in the domination of man over man. Thus, the scientific crisis is, for modernity, an unavoidable dead end.

Although notably involved with articulating a certain thesis on the scientific subject and object, Horkheimer, Adorno and Marcuse deal more with eliminating the idea of a singular scientific subject and focus on dealing with three basic queries:

1. What is science?
2. What social and political meaning does science bear?
3. How is science accomplished?

Critical theory places epistemological questions at the center of its research concerns, particularly relating them to their impact on politics and society. However, when science seeks truth, critical theory does not view it as a *panacea*, nor is science said to have an exclusive claim on progress and innovation. Science is another way for society to pursue truth, rationality, and progress, but it should never serve as a *deus ex machina* in defense of social instrumentality, in order to establish any scientific or political authority by means of scientific works and words. Science, for critical theorists, is rarely neutral or value-free.

For critical theory, even when the objectivistic illusion prevails that everything can be assessed according to measurable facts, the knowing subject always mediates between facts and knowledge. For the epistemology of critical theory, the emphasis is placed on the conscious agent who enlightens facts by means of knowledge. Moreover, "... the empiricist 'fetishism of facts' ignored that facts were, after all, products of collectively developed modes of perception; that we only know 'mediated' facts; and that (even unconscious) theories and methods are the mediators" (Arato and Gebhardt 1998, p. 376). In addition, the knowing subject is not a meritorious individual; it is, rather, the collective subject of a scientific field, or of a whole society searching for truth by means of scientific dialogue that takes place within society, and which is also influenced by it.

From another point of view, for critical theory from the early twentieth century until the early twenty-first, science is not the docile offspring of any political ideology, nor is it the generating factor of ideological constructions or the theologian of a society eager to impose scientific authority. Authoritarianism develops in different forms. For Adorno, Horkheimer, and Marcuse, science avoids reproducing authoritarianism by declining the messianic role of social redemption (For Horkheimer the state of knowledge of a society defines what each society considers or recognizes as ideological and, moreover, converts it into a supposedly commonsense knowledge, which, because of its ideological character, is dogmatic and unwavering). It never loses sight of the concern that part of science's substantive content is to be or to become political, where the rudimentary elements of concepts, methods, and methodology are not merely the coincidental products of historical periods.

By denying the objectification of knowledge and science in a form of political ideology that establishes itself as social mythology, the critical theorists formulate an epistemological argument on the human potential for criticism and reason. They suggest that the knowing subject bearing the inherent capacity to apply dialectics in

the scientific field innovates in science by extricating its social and political irresponsibility or immaturity. It is a moment of sheer Kantianism for the Frankfurt School because it maintains the *a priori* potential and the aim of overcoming immaturity, as well as a bold statement of surmounting the Kantian *Entwurf* for science by means of the dynamics of dialectics toward rational praxis. In Arato's words:

Passive (non-interfering) contemplation belongs to a 'naive' stage where humans confront the world as something 'other': they have not recognized their share in its shaping, nor that the terms in which they relate to it are of their own making, nor that they are dealing with a conceptually or materially appropriated (inner or outer) nature whose terms they can change. When the idea of reason was conceived, it was to do more than regulate the relation between means and ends; it was intended to determine the ends. (Arato and Gebhardt 1998, p. 392)

For critical theory – whether of the first or second generation, and even today – a commitment to think, particularly for knowing and conscious subjects, and to formulate normative theory may potentially result in a commitment to act and generate rational praxis. This aim is bequeathed to the second generation by the first, and it remains Habermas' priority without ever ignoring commitments to normativity. The second generation, with its leading figure Jürgen Habermas, formulates the idea of a universal pragmatics based on the argument that dialogue is transformed into forms of communicative action within the scientific and renders reaching understanding and consensus among scientific participants a feasible potential.

In his epistemological concerns (if not throughout his work as a whole) Habermas opposes positivism (Habermas 1971, 1974). He attributes to the sciences themselves the responsibility for self-reflection on their transcendental capacities. Moreover, doing justice to the substance of historical processes, Habermas attempts to innovate not by rejecting the meaning of transcendental consciousness for knowledge but by combining it with the "objective life context."

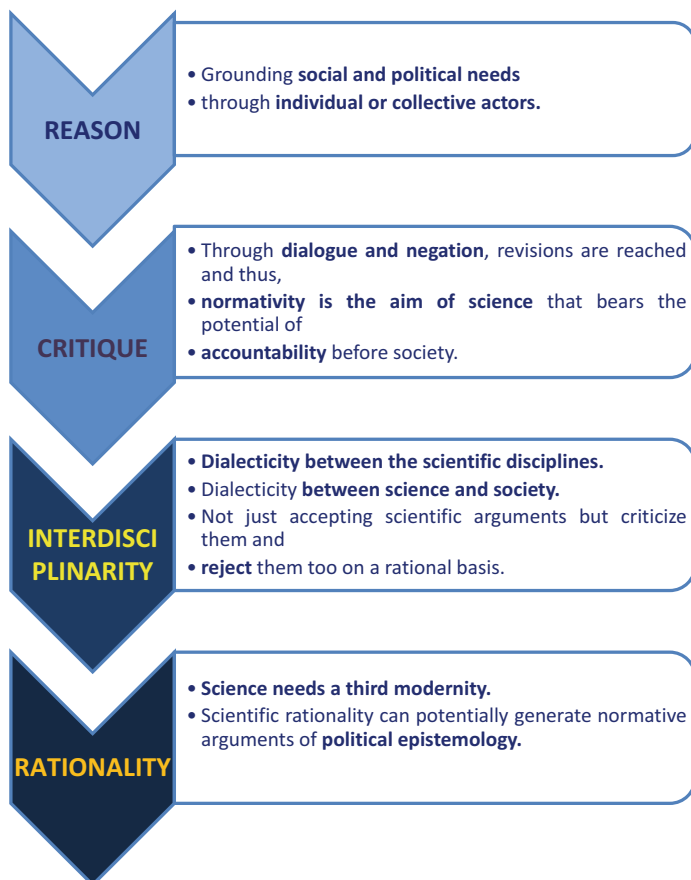
One of Habermas' most notable arguments concerning the sciences is his view that the scientization of politics and social life in general is the other side of the technological control of the sciences over society. The latter takes place by means of ideologizing science, which is rendered autonomous and, thus, delegitimized by the public sphere of society. There is the question of how the colonization of the social becomes feasible by the scientific, rendering the social mute and influenced by ideologies, while the scientific is operational.

Knowledge, for Habermas, is distinct neither from life nor social process. It is not a quantifying procedure, nor is it a simplifying practice in gathering and integrating universal assumptions. Knowledge and science are not the instruments of technical control over an object of the social or over the social as an object. They bear the potential of intersubjective dialogue, which attempts to bridge the gaps between scientific fields, social forces, and research dynamics that endeavor to form social and scientific rationality. Moreover, it becomes evident both for the first and the second generation of critical theorists that normativity is not an external objective of science. Beyond what positivism suggests, science has a normative content that defines what science is, how it performs within the social sphere, and how it is accomplished. Therefore, the critical theory of all the generations attempt a threefold answer to the questions initially posed: first, that science *is* normativity and forms

normative statements on the social realm; second, that there is no neutral science, the meaning of science is its social function and critique; and third, that the means to accomplish social accountability and rationality is to exercise dialectics (its negation toward the instrumental and the irrational for the first generation of critical theorists) and promote communicative action deriving from dialectics (for Habermas) so as to reach understanding.

In more detail, Habermas emphasizes that the normativity of science presupposes an ideal speech situation among participants of either individual or collective character so that potential consensus is reached and rationality is realized through the dialectics of communicative action. The rationality of science that Habermas prioritizes in his thought is the sought-after outcome of realizing theory through practice and of contradicting the irrationality of technological systems of research by means of reason, critique, and interdisciplinarity through the communicative action of the sciences.

The following schema depicts the convergence of the first and the second generation of critical theorists on their four basic epistemological concerns:



The following sections will elaborate on the arguments of the schema and expand on the notion of political epistemology as the normative task of critical theory for the twenty-first century.

3 The Method of Critical Theory

The Frankfurt School's method of exploration (which refers to the first generation) is primarily based on the observation that historical and descriptive accounts might be very important methods of research. However, they still manage to miss the essence of critical theory's arguments, which entail the examination of reason and dialectics with regard to science and epistemology. The critical theory of the Frankfurt School challenges instrumentality whereby human beings also become mere instruments along the lines set out by modern science. The methodology of positivism, which the Frankfurt School attacks, focuses on sciences (in the plural) as systems of knowledge that are separate among themselves and in relation to society, thus constructing a false sense of autonomy for scientific work. Within such systems, each science or scientist aims at articulating an inner set of instructions, according to which deductive statements are produced and through which theory is dissociated from practical rules and praxis itself for the sake of producing immediate scientific results. Thus, the problematic concept of "application" arises, leaving the scientists unprepared to criticize the scientific outcome in any alternative way and unable to decide between the realm of "pure" theory and "pure" praxis as if there could ever be any theory without praxis and vice versa.

In order to deal with what constitutes science, epistemologically speaking, critical theory tackles the problem of scientific laws. The answer remains straightforward: while natural sciences facilitate the formation of scientific laws, it is rather unfeasible to expect the same degree of certainty in the humanities and social sciences. The sciences and, moreover, epistemology cannot merely be a description, nor can they be a rule, method, or methodology. They have to exert critique and influence on something else. Both are consistent with a definite method, which does not presuppose the socially autonomous formation of scientific theory and praxis but derives from society itself. If science is disconnected from what takes place within the social realm, then it is also silenced, normatively muted, and rendered socially indifferent or even redundant. For critical theory, science for the sake of science did not seem a very plausible way of scientific advancement. In fact, the reverse was the case: science becomes valid for both the scientific and the social realm when it stands critically in relation to what takes place socially and convinces people of its eternal relevance.

Science, for the first generation of the Frankfurt School, encompasses foremost the potential for critical reason, formulated because uncoerced dialogue among the sciences has taken place, thus signifying the dynamics of interdisciplinary dialectics. It is crucial for the Frankfurt School to note that dogmatism, positivism, and deterministic laws of understanding the scientific and, successively, the social create a scientific deficit whereby the sciences are unable to react to social and political

crises. Science is by no means an ideological instrument. Furthermore, science is not an instrument. However, unless science deals with and directs its object of research toward the social and political questions set by society itself, and unless it reconsiders which questions it seeks to address, it *shall* become an instrument in the hands of political ideology.

Dialectics, for the Frankfurt School, is not merely a method of research; it is the subject matter of science transforming itself into interdisciplinarity and consummating dialogue among scientific disciplines. It generates dialogue with social science and posits society as the subject, namely, the agent or the acting subject, of science itself. If I could cut a long scientific story short, I would say that critical theory attempts to answer the question “Wozu noch Kritik?” (“Why more critique?”) for science and gives a rather straightforward answer: “Because it is generated by dialectics.” The critique that critical theory articulates and promotes in multiple arguments was (a) dialectical, meaning deriving from dialogical processes and, (b) normative, for it represented a brand-new potential for science. It is normative because it criticizes both society and science in order to reach rationality and consummate it within the social and the scientific. Thus, such a normative critique requires both epistemological and political criteria so as to answer the question “why more scientific critique?”. And the answer remains timely and valid for the twenty-first century too because it appears a valid path to normativity through dialectics and to social accountability as well.

In Horkheimer’s essay ‘Traditional and critical theory’ (Horkheimer 1972), the claim for interdisciplinarity is boldly stated and signified the scientific accountability toward truth, normativity, and rationality. Disclosing truth, for critical theory of the first generation, is a social accomplishment, achieved intersubjectively through dialectics. Science cannot afford to abandon either the social field, for the sake of some vague notion of scientific autonomy, or the dialectical process for the sake of dogmatism. In such terms, it is a clear normative turn that is to be promoted by Habermas and his furthering of the concept of dialectics into a communicative theory and action for science.

Jürgen Habermas, the philosopher and social theorist who innovated critical theory with his notion of communicative action, raises questions as to the methodology the sciences follow, the sort of logical inquiry they adopt, and the criteria they base their scientific objectives on. Habermas perceives the mode of scientific research and analysis as producing not contradiction but the interinfluence of research and analysis. However, precisely because of the mode they opt for, sciences facilitate and promote or discourage dialogue and argumentative exchange. In not being socially isolated by means of dialectics, they become major forces that shape social dialogue and rationality. Where the opposite is the case – and that is the abandonment of dialectics – they predominate by supporting and maintaining the scientization of politics.

In the same way that sciences become the authoritarian force in society by attempting to offer operational approaches to social and political problems, they also become authoritarian for their own field of research. Thus, Habermas associates science with politics by providing a concise guide to instrumental scientific

methodology and the social impact of the scientific sphere as well. The scientific method, then, along with the concept of truth is established as criteria for knowledge "... only from the objective life-context in which the process of inquiry fulfils specifiable functions: the settlement of opinions, the elimination of uncertainties, and the acquisition of unproblematic beliefs ..." (Stockman 1983, p. 67).

In the preface to *Knowledge and Human Interests*, Habermas, in the same manner as Adorno's 'Subject and object', maintains that "... a radical critique of knowledge is possible only as social theory..." (Habermas 1971, p. vii). Moreover, it is essential for the clarification of the subject matter of the chapter, as well as for Habermas' work itself, to note the latter's explanation of what science is and how sciences can be considered as a unified whole composed of different fields maintaining a certain method of research.

For Habermas, science is neither the grand narrative of philosophy nor the eccentric attitude toward the "... actual business of research" (Habermas 1971, p. 4); moreover, it is neither the retreat to a philosophy of science nor the methodology of the sciences. Science is rational thought, deriving from critical consciousness, and directed toward setting dialogue into use, questioning fields of research and exploring normative concepts and social rationality. Epistemology, on the other hand, being, to an extent, the self-reflection of science, is also governed by dialectical thought and questions the social function of the scientific and the socially rational.

Being based upon the previous counterarguments of Horkheimer and Adorno to the assumed validity of commonsense knowledge, Habermas opposes the dogmatism of commonsense knowledge, which appears as the outcome of ideology, and reconstructs the "self-formative process of consciousness," as he states in *Knowledge and Human Interests*. The critique of knowledge – an aim shared by the Frankfurt School of all generations – arises when transcendental consciousness meets the socially perceived demands of science, which are then channeled into a dialectical, self-formative process.

Habermas departs from the latter notion of a dialectical self-formative process of science and introduces the notion of communicative action. He relates and designates not only social relations of uncoerced dialogue but also public communication of scientific subjects against scientific as well as social ideologies. Science is a process and aim, created by scientific dialectics and self-reflection, not the corroboration and absolute result of a socially autonomous prejudgment where science loses its social legitimacy. Science is not the empirically or methodically obligatory end; rather, it concerns itself with the dialectical means to accomplishing knowledge.

The problem and criticism of deduction reappears in critical theory with Habermas' work on epistemological interests and methodological critique. Deduction is associated with purposive-rational action, and because of its claim to methodological certainty, anticipated rules, and decisions, it entails scientific dogmatism and, thus, prejudice. In a wider critique of the symbolic processes of inference, namely, induction, deduction, and abduction, Habermas correlates the threefold schema with the instrumental approaches of pragmatism to describe the learning process by way of cumulative and quantifying criteria.

Dialectics and intersubjectivity acquire a concrete form, which combines empirical research with the “intelligible character of a community that constitutes the world from transcendental perspectives . . . in a self-formative process until the point in time at which a definitive and complete knowledge of reality is attained” (Habermas 1971, p. 135). Where purposive-rational action represents scientific monism and instrumental aims toward technical control of the sciences and society, intersubjectivity represents a potential but not necessary consensus, and, most importantly, it represents the idea of a scientific dialogue that science facilitates and elaborates socially. The idea of communicative action in science becomes the first significant step toward the awareness of ignorance and then of self-formation for knowledge and social claims.

Habermas never ignores the concept of interdisciplinarity and intersubjectivity of the first generation of critical theory and aims at expanding upon its modern understanding by relating it through communicative action, either in the sciences or in society. It is one of the very rare occasions in modern epistemology that the social role of science was manifested in such a direct affiliation with its power over modern politics. Though certainly not for the first time, with Habermas’ work one sees how epistemology took a political turn, avoiding the aporetic considerations of the first generation of the Frankfurt School.

Habermas maintains the political position that knowledge acquires through the elaboration of social claims and the legitimacy attributed to it within the lifeworld and the scientific public sphere. Communicative action among the sciences generated within the lifeworld and the dialogical processes in the public sphere of the sciences commits the scientific realm to redefine rational praxis through normative theory.

However, the notable accomplishment of Habermas is to *innovate the innovations of critical theory* of the first generation. He manages to extend dialectics’ scientific and political dynamics into communicative action and remain loyal to how critique and interdisciplinarity can transform into a communicative rationality for science that remains accountable to society. In the following section, I analyze the scientific as well as the social and political dimensions of Habermas’ *innovation of the innovative* and examine how critical theory’s formulations remain a concrete normative argument of political epistemology that gives shape to the valid task of critical theory for the twenty-first century’s modernity.

4 Critical Theory’s Task: The Normative Turn

Apart from presenting an account of the Frankfurt School and articulating a critique on what was critical for science in the critical theory of the twentieth century, the chapter aims to present *the epistemological task of critical theory for the twenty-first century*. It remains valid and persistently timely throughout the first and the second generation and appears to continue to be the same for the epigones and any third or fourth generation of critical theorists: to criticize the social and political function of science and at the same time remain critical for science itself too.

For the first generation, to articulate a series of critical arguments on science and society is the result of dialectical procedures which are followed by participants in social and scientific dialogue. Critique is the indispensable presupposition of participation in the sphere of science and prevents any lapse into prejudice, myth, or superstition either in science or society. Critique appears more indispensable than any new scientific paradigm in order for science to progress according to critical theorists of the first generation.

The relentless critique on positivism denotes not only a rejection of the traditional scientific methods which appears insufficient to analyze modernity but the formulation of a new argument that could transcend the potential of the scientific paradigm to result in scientific revolution as well. Such a new argument on the part of critical theorists consists in the prioritization of dialectical critique as not only the scientific method but as the scientific conception that safeguards science as modern and not traditional, scientific and not a configuration of myths, as well as being accountable to society. The accountability of science toward society generates much greater and more consistent scientific innovations than the change of paradigms in scientific revolutions. It is the normative task of science to remain critical for both itself and society, and such normativity would be challenged, revisited, and reconsidered in the twentieth century many times by a number of philosophers and sociologists that perceived modernity, dialectical critique, and normativity as inimical if not opposite to the social and political function of science (For a detailed analysis of this argument see Chaps. 1, 2, 3, and 4 of my *Critical Theory and Epistemology: The Politics of Modern Thought and Science*).

Habermas moves in the same direction as the first generation of Horkheimer and Adorno and nevertheless accomplishes to innovate the innovative epistemological legacy of both previous thinkers. He theorizes critique as the task and method of a normative science and sustains Horkheimer's and Adorno's consideration that critique is constituted by the immanent negation of the traditional or, in other words, by the potential to refuse and dialectically reject what is inimical to modernity.

Such a negation would serve in critical theory throughout the twentieth century as the defender of scientific accountability to society. When, for Habermas, critique maintains and generates its validity, the latter can be accomplished without ever losing sight of science's accountability in the social sphere. The dialectical critique deriving from science leads Horkheimer to realize that scientific interdisciplinarity is essential for the profundity of such a scheme. It is only through the dialectical critique between the scientific disciplines that science can manage to innovate on their object as well as their input within the social.

Thus, Habermas realizes that not only a dialectical critique but also practice that keeps the dialectical part but forms action within society is the innovative attribute of critical theory that retains the core of the first generation's argument on interdisciplinarity but is amplified by a conjunction of the critical and its transition into practice. In this manner, communicative action in science is born, and in order to ground his innovation on a firm epistemological basis, Habermas elaborates further on the two main axes of communicative action: first, the potential force of the better

argument and, second, the dynamics for an ideal speech situation which is in its turn formed by the force of the better argument.

Communicative action for Habermas is the bearer of the force of the better argument because his idea of communicative action is the development of the notion of dialectics and interdisciplinarity formulated by the critical theorists of the first generation. Dialectics generates arguments, and it also “promises” a cooperative exploration of truth along with scientific and social rationality. Furthermore, the potential for configuring and realizing the better argument is preconditioned by major aspects such as (1) the willingness and ability of participants of a dialogical critique to be accountable to the public, (2) their equivalent intentionality to include the public in a wider critique and to admit the participation of social factors within scientific dialogue, (3) to acknowledge the equal participation of all involved without undergoing outer or inner coercion of any kind and, finally, (4) the acceptance of the potentiality to reach a consensus that would include all involved parts.

Therefore, the force of the better argument is in Habermasian thought accountable to society, inclusive of negations and divergent arguments, free of any coercion or compulsion, and socially and scientifically rewarding for its ability to generate a consensus of the highest inclusive standard. Hence, Habermas realizes a threefold epistemological achievement:

- (a) He innovates critical theory with the transition from interdisciplinary dialectics to the configuration of what theoretical discourse is.
- (b) He grounds it on social practice.
- (c) He extends it into the presupposition for an ideal speech situation that is promoted by science and applied to society and the conception of the political.

The consummation of an ideal speech situation requires the same vital aspects as the force of the better argument does: the search for truth, uncoerced expression of arguments, and the pursuit of consensus. All the previous orient toward a normative rationality that serves as the pivotal part of science and its social function in order to affect decisions and balance the asymmetries of rational critique and its contingent authoritarian applications.

Habermas’ arguments on the innovation of critical theory in relation to epistemology are not a mere methodological series of propositions bound by a rationalized consistency. It is the continuation of the epistemological pursuit of a critical science that is constantly maintaining a critique by means of dialogue and which challenges social and scientific rationality by means of its normative task, namely, to maintain the political character of science to the extent that the latter criticizes and influences society. It is the pursuit for the *better* argument and the *ideal* speech situation that renders critical theory’s normative task a modern task for the twenty-first century. It is the task to defend modernity through a normative science, and Habermas defends such a task by turning critical theory toward *what the normative and the rational* is in science.

Habermas’ contribution to critical theory is his sheer normative turn. The quest of rationality necessitates that critical theory’s epistemology present a new argument on

what political epistemology is. Normative questions asked within an ideal speech situation guided by practical discourse and the force of the better argument have to be scientifically promoted and established in order to reach society. The task of a critical science is to establish normative questions in order for society to follow such a normativity. Science acts as the creator of normative challenges and attempts to answer established questions along and in cooperation with society. To an equal extent, society engenders its rationality and influences science, politics, and every other social realm but remains also in constant dialogue with the normative questions and attempted answers that science produces. The public dialogue between science and society on what the normative and the rational is remains both in Horkheimer, Adorno, and Habermas the pillar of modernity and perhaps the only hope of modernity for constant innovation in what the social, the political, and the scientific consist in.

In order to challenge the positivists but also ground modernity on a critical basis, critical theorists oscillate from the argument of a normative science to the normativity of modernity and articulate a whole series of critical arguments not on epistemological concerns but on *political epistemology* that is critical theory's contribution to the epistemology of modernity (Marinopoulou 2017).

The political epistemology of critical theory marks a lucid normative turn in modern epistemology. It is the quest for a true or false statement that renders scientific matters valid or invalid and moreover applicable or not. The example of economic theories provides epistemologists of modernity with a clear instance of critique: economic theories can be true or false not just because data and numbers are verified or not but because societies render them so, meaning applicable with evident validation and consequent validity within societies or inapplicable because societies refuse to follow numbers, indexes, or numerical indicators that can be totally verified hypothetically but fail in normative practice.

The political epistemology that critical theory promotes serves as a critique of science *and* society in a binding way that renders such a critique both dialectical and normative as well. It attributes to science the characteristic of a normative "invention" that is created when people ask normative questions. The colonization of the scientific by the social or even the political was a feature of the "old days", namely, of premodern societies. In the old days of epistemology, the prevailing anxiety among scientists was that the political will colonize the scientific sphere and take advantage of it or even worse render it its own instrument. Now, in the modern world, epistemological temptations take the form of absolute divergence between the scientific and the social. The values change: sciences appear inappropriate or even insufficient to answer the normative questions that society poses and are at a loss to produce their own, either questions or answers. Sciences produce their own "logic" which is distant if not irrelevant to social needs and remains unaccountable both to the scientific and the social spheres. In order to advance normative rationality within society, science has to consider its accountability task toward the social and in such a sense to realize its political task, namely, to be in the service of humanity's needs for dialectics, critique, and rationality within the social and the political.

For a critical theory of modernity, science needs a third modern wave of innovation. After the first one in ancient Greece and the second during the French Enlightenment, it is perhaps political epistemology that is compound of normative questions and arguments that will provide modern societies with a scientific as well as social rationality as a firm basis in order to reclaim the modern promise for a rational world.

5 Conclusions and Future Directions

For the Frankfurt School, science is a process of cognition, which contains integrity in its aim and method, as well as in its methodology. Science aspires to maintain strong bonds with social reality, but it also claims to articulate social criticism and put this into practice. On a second level of understanding, science is the process of dealing with contradictions and elaborating on them by means of dialectics.

First-generation critical theory deals with the distinction between subject and object, regarding the subject either as a collective or as an individual actor of science and society. Nevertheless, for Habermas, the object is replaced by another subject, namely, the “co-participant” in dialogue between scientific fields within the process of communicative action. Habermas attempts to find a resolution to the intricacies of the acquisition of knowledge by means of communicative action, the latter being exercised by the scientific subject that produces scientific thought through dialectics, which aims at realizing emancipatory interests. In marked contrast to the latter, when dialectical communication is muted, scientific and social elites are never far away, and knowledge for the degraded “masses” also results from the silencing of dialogue.

The main argument of the chapter concerns the undiminished significance of dialectics not only as a method but also as a process and mode of understanding for the sciences. It is an inherent characteristic of the sciences to generate and deal with contradictions, and, hence, any epistemological understanding of the scientific includes the scientific dialogue on theses and antitheses, as equally important for the evolution of any scientific argument.

For Marcuse, dialectics is the scientific stance toward what remains contentious for the sciences; or, in other words, no scientific neutrality can be accomplished as long as dialectics itself does not claim neutrality. Science is either dialectical or nonexistent. The moment in which critical theory embodies dialectics is, for Marcuse, the moment of negation of the given thesis and principles. In many references, in his work and interviews, Marcuse recognizes that the scientific constructions of modernity in the twentieth century are deprived of such embodiment of a dialectical advance and as such are subject to a scientific deficit that is concealed by means of technological progression.

Although, in many critical theorists’ work, the scientific thesis represents the first advance of scientific development, namely, that there has to be an articulate and coherent position regarding scientific issues, what in essence constructs a moment of scientific reflection is the acceptance of critique and probable negation, which is encompassed either in the negation or the synthesis of the two. Critical theory then

brings criticism to bear on the sciences, not from the position of the grand inquisitor, but rather from the point of view that allows for science to take an expressive position and simultaneously include the negation of a thesis and the potential synthesis, serving a self-reflective attitude toward science and its objectives.

Dialectics is a form of scientific entirety, including a certain position, its negation, and its alternative. However, the negation is not a reactionary moment within the scientific stance. It is the articulation of a critical argument that opposes a given thesis. For Adorno (<http://www.youtube.com/watch?v=aIQpJNxGa90>), critical theory is not a scientific field itself; rather, it constitutes the moment of reflexivity for the sciences. It can indicate that science is not a field of totality and homogeneity; on the contrary, it is a site of disagreement, negation, and opposition to the given and taken for granted.

In my understanding, science constitutes simultaneously the formation of questions and the potentiality for answers. The culture of scientific discourse that Habermas introduces and analyzes throughout his work extends from the notion of a critical theory (as originally understood by Horkheimer) to a critical science. In order to formulate a rational scientific answer, science has first to designate a concrete scientific question and a dialectical problematic.

During the late modernity of the twentieth and twenty-first centuries, critical science maintains that its aim is dialectical, in terms of producing social criticism, whereas epistemology acquires a political character. A rational reconstruction of the sciences will not become the scientific concern of modernity because philosophy occupies the position of the scientific consciousness for modern science. Rather, a rational progression of the sciences will take place when epistemology becomes political and, therefore, socially influential. The main abovementioned points raised claims that reinforce the potential accountability of science in its relationship with society. Through the formation of a normative theory, the task of political epistemology is to initiate and maintain the promise and potential of conscious subjects toward rational praxis.

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Positivism and Realism

9

Priya Khanna

Contents

1	Introduction	152
2	Positivism	154
2.1	Meaning	154
2.2	Emergence of Western Science and Positivist Notions	155
2.3	Social Sciences and Comte's Classical Positivism	156
2.4	Logical Positivism	157
2.5	Post-Positivism	158
2.6	Legacy of Positivism and Post-Positivism in Health Social Sciences Research	160
3	Realism	161
3.1	Scientific Realism	161
3.2	Scientific Antirealism	162
3.3	Critical Realism	164
3.4	Implications of Critical Realism in Health Social Sciences Research	165
4	Conclusion and Future Directions	166
	References	167

Abstract

Theory and practice of research in health social sciences involves a unique synergy of a range of quantitative, qualitative, and hybrid methodologies derived from parent disciplines of medicine, nursing, and various other branches of social sciences such as sociology and psychology. While the methodological diversity enhances the scope of research and implications of research findings, it also renders the necessity for the investigator to explicitly address the implicit theoretical stances and philosophical assumptions underpinning the evidentiary claims. Still inherent among the investigators in health social sciences is to present their evidentiary claims in binary terms of whether an intervention/

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151

initiative worked or not, as opposed to why it worked and for whom. This tendency to gauge the strength of evidence in terms of objectivity and replicability seems to be emerging from the deep rooted desires for control and prediction of phenomena under investigation as opposed to meaning-making. While taking the readers on a brief journey through the emergence of history and philosophy of western science, this chapter aims to provide a deeper understanding of two major philosophical foundations of research methodologies: positivism, a theoretical stance underpinning rigor and objectivity in science and scientific method, and realism, an ontological perspective examining the truth of mind-independent reality. It is suggested that a closer inspection of emergence of scientific inquiry and its underpinnings will facilitate a better understanding of research designs and outcomes, especially for contemporary complex environments in which various initiatives in health social sciences operate.

Keywords

Positivism · Realism · Ontology · Epistemology · Research · Health · Social sciences

1 Introduction

Look round

For evidence enough. 'Tis found,

No doubt: As is your sort of mind,

So is your sort of search: you'll find

What you desire.

(Robert Browning, *Easter Day*)

No matter how the term, “*research*” is defined, regardless of discipline and of its typologies, it is ultimately a quest to deepen our understanding of the world through expanding our knowledge of it. When one looks at the more specific definitions of research, the words that often appear include: “*systematic*,” “*investigation*,” and “*evidence*.” To understand how best a systematic investigation can be undertaken to yield evidence that can be translated or adapted in other similar contexts for desired purposes, one needs to understand what really *is* meant by these terms. The first two terms are linked to the theory of action or methods of research (methodology) impacting the evidentiary claims, which in turn, are influenced by theory of how we know the object of investigation (epistemology). Closely linked to both, methodology and epistemology is the understanding of the nature of the “*reality*” or essence of the object itself (ontology). This triad of theoretical underpinnings of

research can be best understood against the backdrop of historic emergence of the pursuit of knowledge and inquiry itself (see also ► [Chap. 6, “Ontology and Epistemology”](#)).

Until Middle Ages, the world view in most of the world civilizations, especially in the Western part of the world was organic, where people lived in small, cohesive communities, and where theology guided the belief systems. The quest of knowledge, in this organic world, was focused on meaning and significance using both reason and faith. With the Scientific Revolution, the organic and spiritual worldview was gradually replaced with a “world-as-a-machine” view, and the focus of the quest shifted from meaning and significance to control and prediction (Capra 1982).

The worth of the quest of knowledge began to be gauged by the level of certainty, validity, and objectivity of scientific claims. As one travels through the journey of philosophy of science, this modernist era marks the phase of positivism – a theoretical commitment where the nature of inquiry was characterized by methodological objectivity of verifying only that is verifiable, rendering metaphysical speculations to be meaningless (Hjørland 2005). As Wight (2002) describes, positivist era laid the foundations of social science as a discipline where the principles of scientific claims governed the legitimacy of social inquiry as well.

The limitations of positivist worldview became apparent with the extraordinarily intellectual feats in modern physics such as quantum theory, as well as new wave of profound conceptions in philosophy of science which illuminated falsifiability, fallibility, and theory-laden nature of scientific knowledge. Post-positivist era also led to the emergence of alternative theoretical and methodological commitments such as interpretivism especially in social science inquiry including healthcare education which led to the popularity of qualitative and mixed-methodological research paradigms (Grant and Giddings 2002).

While we do take pride in claiming that social inquiry no longer needs to emulate its cousins in natural sciences, and the yardstick against which we assess methodological rigor is no longer limited to positivist underpinnings, the legacy of positivism still lingers on. As Crotty (1998) highlights, qualitative research, if carried out to establish evidence as facts and truths, is rooted within positivist underpinnings. For instance, an ethnographic investigation of a healthcare intervention will be usually represented as qualitative study (see ► [Chap. 26, “Ethnographic Method”](#)); however, if the findings are concluded in binary terms of whether “it worked or not” rather than “for whom and why,” it is still underpinned under positivist framework. One can perhaps argue for the need for conclusiveness of evidence for its translation into practice, especially in biomedical sciences. The unsurpassed authority of randomized controlled trials (RCTs) as gold standard in evidence-based medicine reflects this urge for equating evidence with “Truth” (see also ► [Chap. 37, “Randomized Controlled Trials”](#)). This pursuit of truth or reality is an ontological issue, and as we shall see later in the chapter, understanding of reality is separate from understanding of methods of knowing the reality.

While positivism is a theoretical perspective that suggests certain epistemic commitments, the ontological position closely associated but not limited to

positivism is realism. In this chapter, I shall explore major types and tenets of realism, mainly scientific realism, anti-realism, and contemporary realist perspectives such as critical realism which is compatible with constructionist epistemological frameworks.

Traversing through the history and philosophy of science, this chapter aims to provide a deeper understanding of emergence of positivist perspectives and realist ontological commitments that laid the foundations of methodological rigor in both natural as well as social sciences research. Such an understanding of historic emergence will also aid in clarifying closely related but distinct concepts such as empiricism versus rationalism versus empirical research, and empiricism versus realism.

2 Positivism

2.1 Meaning

The “positive” in positivism does not imply “good” or synonyms associated with it, but it means something that is “posited” or postulated. This is in opposition to “natural,” as in natural law or natural religion, where the content emerges from the nature. On the contrary, positive religion or positive law is not arrived at by speculation, but enacted and adopted by proper authority. In context of science, and later in social sciences, what is “posited” or given from direct experiences is what is observed by scientific method as opposed to metaphysical speculations (Crotty 1998). The essence of positivism, in its various conceptualizations, is that there is a basic scientific method which is same across both natural and social sciences. Positivist school of thought believes in the “thesis of the unity of science,” which means that only way by which social sciences can match the achievements of natural science in explanation, prediction, and control of phenomena being observed is by applying the methods of natural science (Lee 1991).

Positivism is not a univocal concept. Its meaning has evolved with time and can be conceptualized in three ways: positivism as a philosophical and political movement originating from French Philosopher Auguste Comte’s (1798–1857) commitment to social evolution; logical positivism as well-defined philosophy of science; and methodological positivism which refers to epistemological beliefs underpinning scientific research methods and practices (Riley 2007). While positivism embodies certain epistemic commitments, it is by itself not an epistemology unless the definition of epistemology is stretched to include theoretical stances associated with theory of knowledge (Wight 2002; see ► Chap. 6, “Ontology and Epistemology”). The genesis and dominance of positivism as a philosophical and political movement, until second half of nineteenth century, is attributed to the father of modern sociology, Auguste Comte, also regarded as the founder of positivism. The origin of positivist notions, however, can be traced much earlier in the long history of early Enlightenment thinkers in the Western philosophy and in the emergence of modern science and its philosophy.

2.2 Emergence of Western Science and Positivist Notions

Capra (1982, 1992) and Russell (2013) provide a very enriching account of history and philosophy of Western science, and emergence of modern science, and scientific method. The Western science and the philosophy, into which it was originally subsumed along with theology, can be traced back to the beginning of sixth century with the Greek philosopher Thales, a native of ancient city, Miletus. The speculations of Thales, along with other two philosophers of Milesian Triad, Anaximander, and Anaximenes, can be regarded as the earliest scientific hypotheses. The late sixth century saw the influence of mathematics upon philosophy and theology with the works of Pythagoras who laid the foundations of geometry. The combination of scientific rationality, theology, and philosophy was carried on by other prominent philosophers, the most revered of which was Socrates, who was primarily concerned with critical examination of abstract concepts through dialogues. Following Socratic legacy, Plato and Aristotle continued systematic metaphysical speculations. Aristotle's influence, which was great in many different fields, was the greatest in logic and retained his authority in it throughout the Middle Ages. The first person often regarded to defend the autonomy of science as a distinct body of knowledge was St Thomas Aquinas who combined Aristotle's comprehensive system of nature with Christian theology using reason and faith. Hence, the purpose of medieval science, unlike modern science, was to understand the meaning and significance of things using both reason and faith, rather than prediction and control of phenomenon.

With the gradual decline in the dominance of the Church, and with the birth of the Renaissance, the medieval science changed radically in sixteenth and seventeenth centuries with the Scientific Revolution that began with Copernicus followed by Kepler. The end of sixteenth century saw the rise of the greatest of the founders of modern science, Galileo (1564–1642), who was the first to combine scientific experimentation using mathematical language to formulate the laws of the nature. Around the same time as Galileo was devising ingenious experiments in Italy, Francis Bacon (1561–1626) set forth empirical method of science in England primarily based on induction – combining together observed facts to form generalizations. The Baconian spirit of scientific investigation began to replace the organic view of nature with the metaphor of world-as-a-machine, and this shift in the worldview was completed by two towering figures of the seventeenth century, Descartes and Newton.

Rene Descartes (1596–1650) is usually regarded as the founder of modern philosophy, but he was also a brilliant mathematician. Descartes based his views of nature on fundamental division into two independent realms of mind (*res cogitans*) and matter (*res extensa*). The Cartesian dualism of mind as separate from matter formed the basis of the belief that world could be described objectively through analytical and rational reasoning. On one hand, the Cartesian division formed the foundations of classical physics, but on the other hand, it led to the mechanical and fragmented world view of nature as a perfect machine governed by exact mathematical laws. Limitations of the mechanistic world view, however, were not recognized until twenty-first century as we shall see later in this chapter.

The man who realized the Cartesian dream and completed the Scientific Revolution with the grand synthesis of the works of Copernicus, Kepler, Bacon, and Galileo was Isaac Newton (1642–1727). Synthesizing the Baconian empirical and inductive method with Descartes' deductive reasoning, Newton laid the foundations of classical physics in which the material particles moved in absolute space and time governed by the force of gravity. Newtonian-mechanistic model of classical physics dominated the Western scientific thought from the second half of seventeenth to the end of nineteenth century. While the Newtonian atomistic physics provided the basis of understanding the laws governing the universe, Locke developed an atomistic view of society by attempting to reduce observable societal patterns to the behavior of its individuals. He asserted that humans are born “*tabula rasa*” – a clean slate on which knowledge acquired through senses can be imprinted.

Within positivist notions, one can see two distinct epistemological positions – classic empiricism versus rationalism. Classical empiricism of Locke and Hume, for instance, regards observations and sensory experiences as the only method to gain knowledge; whereas rationalism, in its purest form, argues for preestablished conditions, categories, or inborn structures for obtaining knowledge. Rationalists prefer deductive rather than inductive methods for obtaining evidence. As we will see later in the chapter, the classic empiricism was combined with rationalism by a school of positivism, logical positivism (Hjørland 2005).

2.3 Social Sciences and Comte's Classical Positivism

The legacy of Descartes, Newton, and Locke was crucial to the developments in social sciences which paralleled scientific progress in natural sciences. Early Enlightenment thinkers in social sciences, such as Rousseau for instance, were concerned about the progress of humanity by conceptualizing a state-level society based on equality and agreement between the governed and those who govern. The man, however, responsible for laying out plan for mechanistic social sciences and conceived the discipline of “sociology” and coined the term itself was Auguste Comte. While his mentor, Henri de Saint-Simon may have been the originator of the positivist school of social sciences, it was Comte who elaborated the thought in series of major books. In his six-volume work, *The Course of Positive Philosophy*, Comte proposed his famous law of three stages through which the human mind, individual human beings, all knowledge, and world history is developed. The first stage is the theological stage dominated by search for the essential nature of things as explained by the existence of gods and supernatural forces. From the primitive stage of polytheism, religion evolves towards monotheism as the ultimate belief of the theological stage. This is followed by the metaphysical stage in which explanations are given in terms of abstract entities as opposed to supernatural agents. The positivist stage is the last and highest stage which involves reliance on empirical data, reason, and development of scientific laws to explain the phenomena. The

law reflects Comte's idea of close association between intellectual progress and social evolution.

The second pillar of Comte's positivism is the classification of sciences into a hierarchy with mathematics and astronomy as its base, followed by physics, chemistry, biology, and culminating in sociology – the science of society. Comte's view of hierarchy of the six fundamental sciences provides justice to the diversity of the sciences without thereby losing sight of their unity (Bourdeau 2008; Bernard 2011; Ritzer and Stepnisky 2017).

Often, Comte's reductionist view of reducing all knowledge into mathematics is equated to his search for objectivism via mathematical precision. This may not be an accurate interpretation, as Crotty (1998) points out that Comte acknowledged the interdependence of human consciousness and "the social," as well as the role of theory in undertaking empirical research.

2.4 Logical Positivism

Inspired by the late nineteenth- and early twentieth-century advancements in mathematics, physics, biology, and social sciences including psychology, which were all pursued independently from philosophy, a philosophical movement called logical positivism, more suitably known as logical empiricism, originated in Austria and Germany in the 1920s (Hjørland 2005; Bernard 2011). The logical positivists, also known as the Vienna Circle, composed of mathematicians, philosophers, and physicists and primarily sought to use the rigor of mathematics for the study of philosophy, which at that time was losing its hold on natural as well as social sciences (Richard 2017).

Logical empiricists attempted to combine the classical British empiricism and continental rationalism with the method of logical analysis aiming to distinguish between analytical and synthetic propositions. They proposed that all meaningful statements are either empirical, i.e., observable and verifiable by experience (synthetic *a posteriori* propositions), or they are logical such as mathematical statements which are analytical *a priori* propositions. The statements that fall into neither of the two categories are meaningless. Science and philosophy should attempt to answer only scientifically answerable questions. In other words, no statement is meaningful unless it is capable of being verified, and this was the basis of "verification principle" – central tenet of logical empiricism, inspired by the works of Wittgenstein, an influential twentieth-century philosopher who was primarily concerned with demarcating valid and invalid use of language. The purpose of philosophy, according to logical empiricists, was to define and clarify the meaning of statements, and to distinguish statements that can be verified and from those "meaningless statements" such as metaphysical views, ethical values aesthetics and religious beliefs, which although had emotional associations but lacked cognitive meaning (Kincaid 1998; Hjørland 2005).

2.5 Post-Positivism

The influence by Logical positivism began to wane out by mid-twentieth century primarily by increasing sense of dissatisfaction with the positivist model of scientific knowledge which was perceived as unrealistic. With the revolutionary developments in physics, biology, psychology, and as well as philosophical perspectives in science, it was recognized that science is indeed a social enterprise undertaken by fallible humans (Klee 1999).

Two fundamental theories of modern physics, theory of relativity and quantum theory, transformed the image of the universe as a machine to a dynamic and holistic whole with interrelated parts. The extraordinary intellectual feat of Albert Einstein laid the foundations of collapse in the faith for dualistic thinking. The investigations of atom and subatomic particles further provided insights into matters being an abstract entity with dualist characteristic of particle as well as wave, depending upon how they are being observed, hence questioning the Cartesian division of observer and observed.

As far as the laws of mathematics refer to reality, they are not certain; and as far as they are certain, they do not refer to reality. (Einstein (1921) in the essay 'Geometry and Experience' In: Reichenbach and Cohen (1978, p. 33))

Developments in quantum theory and the new physics, led by eminent physicists including Planck, Einstein, Bohr, de Broglie, Schrodinger, Pauli, Heisenberg and Dirac, led to significant and fundamental changes in the concepts of space, time, matter, object, and causality. The scientific community during the second half of twentieth century began to realize that the world and its entities does not exist as independent and isolated building blocks but as a unified whole with complicated web of relations between various entities, including the observer and his consciousness (Capra 1982). The twentieth-century theoretical physics is now working grand unification of four major forces of nature by combining theory of relativity and quantum physics (Dardo 2004), and this endeavor towards achieving the "final unity" parallels eastern philosophical assertions of unity in terms of soul consciousness as the very basis of existence.

Modern physics' view of seeing universe as a unified whole are echoed in social sciences by Max Weber who asserted that social realities need to be understood from the perspectives of the observed than the observer, and in totality than in isolation, thereby laying the foundations for modern interpretivism in sociology (Fox 2008).

Apart from interpretivist movements in social sciences, developments in feminism, post structuralism, critical and constructivist psychology further added to the dissatisfaction with positivist perspectives (see also ► [Chap. 7, "Social Constructionism"](#)). Cochran (2002) aptly articulates that positivism's main problem is not its attachment to scientific method as such but rather its commitment to what John Dewey, the leading proponent of pragmatism, called the "quest for certainty." Dewey's approach to social science focused on embracing experience as it is lived, rather than generating universal abstractions about a "real world," which is deliberately removed from everyday practice.

Parallel to the developments in natural and social sciences, “new” doctrine emerged among twentieth century philosophy of science, which although comprise of divergent views but acknowledge science as a social enterprise subject to fallibility. Prominent postmodern philosophers of science include Popper, Kuhn, Feyerabend, Lakatos, and Tolumin. This chapter briefly summaries Pooper and Kuhn’s perspectives on post-positivist views of science and scientific knowledge.

Karl Popper (1902–1994) was one of the most influential philosophers of science in the post-positivist era. Although he had early associations with the Vienna Circle, his view of how scientific knowledge is developed is remarkably different from that of logical positivists. Popper substituted the idea of verifiability with the notion of falsifiability. In Popper’s hypothetico-deductive scientific method, scientific theories are proposed as hypothesis which are inferred from observations but are conjectures or guesses; propositions are then deduced from these conjectures, which are then tested using observations or experimentations. Those hypotheses shown to be false must be revised or replaced. Hence, it is falsifiability of a theory and not verifiability that renders necessary condition for it to be scientific (Achinstein 2004; d’Espagnat 2006).

Crotty (1998) further explains that even if the theory has survived every failed attempt for its refutation, the theory is still “corroborated” and cannot be inferred as true as it takes only one example to falsify the theory. Popper’s idea of tentativeness of scientific knowledge is in complete contrast with the objectivist epistemology of positivism.

The leading contemporary thinker, who provided a very thorough understanding of what science is, and how scientific knowledge is developed over a period of time, was Thomas Kuhn (1922–1996), an American physicist, historian, and philosopher of science. His most popular work, *The Structure of Scientific Revolution* (SSR), had an impact far and wide beyond the boundaries of philosophy of science. In SSR, Kuhn provided a model of development of scientific knowledge within a given field of inquiry in which the field evolves through a series of stages in a cyclic manner. The field evolves through a prescientific immaturity to a peaceful stable “normal science,” where scientific progress is made through “puzzle-solving” activities in which most scientists are normally engaged. The package of theoretical assumptions, beliefs, rules, and concepts in which normal science works is collectively termed as “paradigm” by Kuhn. Scientific activity is carried out in line with the parameters and boundaries set by the dominant paradigm in the field of inquiry. The next stage in the scientific development comes when, in the normal science, the theoretical or experimental results do not fit the reigning paradigm (called anomalies) and the fundamental principles and assumptions of the field are called into question. This leads to scientific revolution which involves “paradigm shift” involving radical new ways of thinking and solving unsolved puzzles and eliminating anomalies.

Acknowledging the criticism of “paradigm” being insufficiently precise, Kuhn in the second edition of the book in 1970 added a postscript where he replaces

the “paradigm” with the expression “disciplinary matrix” where “disciplinary” refers to the common possession of the practitioners of a particular discipline, and “matrix” is the ordered elements of various sorts, each requiring further specification (Klee 1999; Achinstein 2004). Sharrock (2002, pp. 13–14) summarizes Kuhn’s antagonistic views with his logical empiricist predecessors and with Popperian logic, some which as:

There is no sharp distinction between observation and theory.

Science is not cumulative, and does not have a tight deductive structure. . . methodological unity of science is false as there are lots of disconnected tools used for various kinds of inquiry. Science is in time and is historical.

2.6 Legacy of Positivism and Post-Positivism in Health Social Sciences Research

In several ways, the tenets of logical positivism still have a major influence in methodological underpinnings, not only in experimental and biomedical sciences but in social science research as well. Hjørland (2005) summarizes two major influences of local positivism in contemporary research methodologies in social and healthcare sciences. Firstly, to ascertain “veracity” of research findings, a hierarchy of scientific methods has been established, under the influence of evidence-based movement, with randomized controlled trials (RCTs) as the highest form of evidence and qualitative evidence at the very bottom. This notion of assigning more weight to the evidence generated in a strict scientific method limits its sense-making and informative capacity. The dominance of RCTs as the highest form of evidence still perpetuates in health social sciences including nursing and medical education (see ► Chap. 37, “Randomized Controlled Trials”). The multiple or mixed methodology approach is yet to establish its credibility especially in research areas where RCTs are still dominant and multiple qualitative methods are only used as secondary sources of evidence (see ► Chaps. 39, “Integrated Methods in Research,” and ► 40, “The Use of Mixed Methods in Research”).

Secondly, the legacy of logical positivism still continues in much of the quantitative research which uses statistical methods to test hypotheses and to draw correlational inferences between the variables using purely mechanical and logical process. Correlation does not imply causation — but refusal to draw causation is rooted within logical positivist’s rejection of metaphysics. The emphasis on “observations” (empiricism) and “verifiability” (all observers agree on what is being verified, i.e., interrater subjectivity needs to be reduced) creates an overemphasis on reproducibility of data as opposed to its usefulness/adaptability.

Positivism, as described earlier in this chapter, is a philosophical stance that embodies objectivist commitments to its epistemology. However, understanding of epistemology is incomplete without indulging ourselves in the ontological discourse, which in the case of positivism is realism.

3 Realism

The two crucial questions that philosophers, since time immemorial, have engaged themselves in are: what is the nature of existence or reality (i.e., what “is”), and how can we know what “there is”? The latter is an epistemological question, and the former deals with ontology (see ► Chap. 6, “Ontology and Epistemology”). The distinction between the two is reflected in the works of two eminent physicists of twentieth century – Bohr and Heisenberg. While Heisenberg’s uncertainty principle is an epistemological argument in terms of science’s inability to determine location and momentum of subatomic particles simultaneously with accuracy, Bohr questions the nature of particles itself, which is an ontological issue (Crotty 1998).

Roy Bhaskar, a British philosopher, whose work on critical realism will be discussed later in this chapter, cautions us against a metaphysical dogma, which he terms as “*epistemic fallacy*”; i.e., one cannot reduce the statement about the world (ontology) into knowledge of the world (epistemology) (Bhaskar 1975). In several ways, positivism is underpinned by epistemic fallacy as ontological questions in positivism seem to be described and understood in terms of its epistemological beliefs. This creates confusion for the position of positivism itself in philosophical realm. Some scholars have regarded positivism as a form of scientific realism (Cacioppo et al. 2004); others have designated it as a “theoretical perspective” (Crotty 1998), while some other scholars have called it as a paradigm (Guba and Lincoln 1994). Epistemic fallacy also gives rise to misconceptions about the position of realism in relation to positivism.

Realism, in its simplest form, is an ontological position, which assumes that reality exists independently of our perceptions of it. Reality, in realism, refers to all that is “out there,” i.e., entities, objects, forces, structures, and so on. A healthcare researcher, using a realist lens, would view the concepts of “disease” and “diseaseness” as “things in the world” independent of his or her perceptions. Realism can be contested against idealism, specifically, Kantian *transcendental idealism* where objects of human experience and their attributes do not possess any existence of themselves, outside of our mind (d’Espagnat 2006). There are several traditions and variants of notions of mind-independent reality. While some realists perceive reality to be completely independent of our perceptions such as in naïve realism, whereas others, such as critical realists, attempted to integrate realist ontology with a constructivist epistemology. This chapter covers two basic tenets of two major realist thoughts – scientific realism and critical realism.

3.1 Scientific Realism

Scientific realism is a belief about the truth in reference to scientific theories in describing the observable and unobservable entities, which primarily are regarded as “mind-independent.” Scientific realism, then, is the theory that the objects of scientific enquiry exist and act, for the most part, quite independently of scientists and their activity (Bhaskar 1975).

Scientific realism can be viewed in terms of three dimensions or commitments. In ontological terms, scientific realism is committed to the mind-independent existence

of the reality. The reality, which scientific theories describe, is largely independent of our thoughts or theoretical commitments. This position of metaphysical realism is contested by antirealists, primarily idealists for whom there is no reality external and independent of the mind. In epistemic terms, scientific realism is a positive attitude about the truth or approximate truth of scientific theories and theoretical claims about the observable and unobservable entities in the world. The third commitments is the sematic dimension of scientific realism, wherein the theoretical and empirical claims about the objects, events, processes and relations, and other entities, whether observable or unobservable, are to be construed as having truth values.

Human sensory capabilities render the distinction between observable (such as trees, moon, stars), and unobservable (such as distant galaxies, electrons, forces). Scientific realists typically assume that theories as described by “mature” sciences such as physics are usually true, or approximately true reference to the reality they purport to describe. If space, time, forces, atomic particles exist and have certain properties, they exist independently of our perceptions of them, and their existence is best described by scientific theories. This view is often contested by antirealists, some of which adopt an epistemically positive attitude only with respect to the observable, as we shall see later. Valid experimental arguments in favor of scientific realism were provided by Jean Perrin, French physicist who studied Brownian motion of particles suspended in liquids. Perrin’s arguments can be best simplified as

Molecules exist

Molecules are unobservable entities

Therefore, unobservable entities exist. (Achinstein 2004, p. 328)

Defenders of scientific realism such as Richard Boyd and Stathis Psillos have defended a more demanding view of scientific realism. It is also claimed that scientific realism is about the aim of science wherein science provides us theories what the world is like, and acceptance of the theory involves the belief that it is true (Achinstein 2004).

A strong defense in favor of scientific realism comes from Putnam’s claim that realism is the only philosophy that does not make the success of science a miracle. Putnam, initially a realist but later affiliated himself more with the transcendental idealism, in his “*no-miracle argument*,” proclaimed that the success of scientific theories in facilitating empirical predictions and explanations with remarkable accuracy can only be explained by realist explanation that the best scientific theories are true or approximately true description of the mind-independent reality. This belief in the realism is justified as a case of inference to best explanation (Boyd 1983; Bird 2006; Chakravartty 2011).

3.2 Scientific Antirealism

Any philosophical stance that opposes realism along its metaphysical, epistemic, or sematic commitments is antirealism. Antirealism comes in various forms, but

the two major positions that are discussed here are instrumentalism and empirical constructivism; the other forms include historicism, social constructivism, pragmatism, and postmodern frameworks such as feminist approaches.

Instrumentalism, a form of empiricism, regards theories as instruments for making predictions. Logical empiricists were advocates of this view. As we saw in the earlier sections of this chapter, logical empiricist advocated for rationalizing the meaningfulness of the statements and felt that terms for observable entities have no meaning all by themselves, and they acquire meaning by being associated with the observables. For instrumentalists, the appropriate question is asked is not about the truth of a theory but if it is empirically adequate, i.e., if it makes accurate predictions about observable consequences (Bird 2006).

Another form of antirealism is constructive empiricism, popularized by Van Fraassen (1980), who defines it as:

Science aims to give us theories which are empirically adequate; and acceptance of a theory involves as belief only that it is empirically adequate. (The Scientific Image 1980, p. 12)

The central tenet of *constructive empiricism* is the notion of empirical adequacy which implies that a theory is empirically adequate if its observable consequences are true. While this position is compatible with metaphysical view of realism in regards to its interpretation of a theory as true or false, its opposition for realist is epistemic as it believes in the truth of the scientific theories in terms of observables and is satisfied to claim unobservable as true or false without the need of belief in their existence (Bird 2006; Chakravarty 2011).

Constructive empiricism sometimes is also regarded as a form of instrumentalism owing to its position towards observables. One extreme side of antirealism is the view that reality is entirely dependent on our mind (transcendental idealism). A contemporary version of this form of idealism is social constructivism, which in scientific antirealist terms would imply that it is the scientists/researchers who decide what entities exist and in that process they “construct” the entities (see ► Chap. 7, “Social Constructionism”).

In the realm of health social sciences, understandings of the theses of antirealisms may provide insights into assessing the “unobservable” competencies. In medical education, for instance, competency-based movement has created impetus on assessing not only clinical or academic competencies but non-academic competencies (such as empathy, team-skills, interpersonal skills, and so on). While clinical skills can be directly observed and inferred (by using tools such as Direct Observation of Procedural Skills (DOPS) and Objective Structured Clinical Examination (OSCEs)), it is the assessment of nonclinical skills which is problematic. The principle of “observability,” which in empirical sense demarcates theoretical and nontheoretical statements can provide some insights into how better can we understand the problems in programmatic assessment which links together various assessment of various clinical and nonclinical competencies.

3.3 Critical Realism

The most prominent form of scientific realism in the social sciences is critical realism, usually associated with the works of British philosopher Roy Bhaskar (1944–2014). In his seminal work, *A Realist Theory of Science* (1975), Bhaskar's version of critical realism (which he initially labelled as transcendental realism) seems to originate from his reflections on two issues in Western philosophy of science. Firstly, he questioned the dominant *ontological monovalence* in terms of reality being viewed as unstructured, undifferentiated, and unchanging. Secondly, he put forward the notion of *epistemic fallacy* – statements about the world (reality) cannot be reduced into statements about knowledge of the world (epistemology), because realism is a theory of *being*, and not a theory of knowledge. Bhaskar's theory, therefore, is polyvalent in terms of dimensions of knowledge, as well as reality (Bhaskar 1975).

Science, according to Bhaskar, is a product of man as a social and historic being. While science is made by man, with locus of existence being human mind, it is directed upon objects that exist independently of man. There are, therefore, two dimensions of science: social dimension wherein science is a product of human society and an objective dimension which comprises objects being studied by science. Two kinds of objects correspond to these two dimensions of science: independent or objective objects or things (physical as well as social processes) form the intransitive dimension of science, whereas objects such as theories, paradigm, models, and methods form the transitive dimension of science.

To establish the objectivity of intransitive dimension, Bhaskar viewed his version of realism as an alternative to two competing or rival philosophies – classical empiricism (knowledge a product of experience) and transcendental idealism (knowledge a product of human mind). A common element in both the rival philosophies is that the existence of reality is dependent of what can be experienced, and Bhaskar referred to this commitment as empirical realism. In this way, empirical realism rejects the intransitive dimension of science: the world of which science seeks knowledge is not independent of man; on the contrary, it can only be described in relation to man and his cognitive activity (Evangelopoulos 2013).

Bhaskar's third position, transcendental realism, regards the objects of knowledge as the structures and mechanisms that generate phenomena and the knowledge as produced in the social activity of science. These objects are neither phenomena (empiricism) nor human constructs imposed upon the phenomena (idealism), but real structures which endure and operate independently of our knowledge, our experience, and the conditions which allow us access to them. According to this view, both knowledge and the world are structured, both are differentiated and changing; the latter exists independently of the former (though not of our knowledge of this fact), and experiences and the things and causal laws to which it affords us access are normally out of phase with one another (Bhaskar 1975, p. 15). Bhaskar's view of ontology is primarily to seek the answer to the question, "what must be the

world like for science (cognitive activities- sense perceptions and experimentations) to be possible?" The "world," according to Bhaskar, consists of mechanisms and not events. Mechanisms combine to generate the flux of phenomenon that constitutes the actual happenings of the world. Causal structures and generative mechanisms are intransitive, i.e., are *real* and distinct from the pattern of *actual* events they generate, which in turn are distinct from the experiences in which they are apprehended. Hence, reality, as per Bhaskar, is stratified into the realms of the real, the actual, and the empirical. Science, therefore, is a social activity directed towards understanding the generative mechanisms that underpin the observable events.

3.4 Implications of Critical Realism in Health Social Sciences Research

Critical realists retain an ontological realism in the sense of existence of a real world independent of our perceptions, and at the same time they accept epistemological constructivism and relativism, i.e., the understanding of the reality is a function of our perspectives. The relativist epistemology of critical realists legitimizes multiple accounts and interpretations of reality, and this has profound implications for health social science research methodologies including qualitative and mixed-methods research (Maxwell 2012).

Bhaskar's version of critical realism, in particular, provides not only a holistic and emergent view of ontology, its concept of generative mechanisms to explain causal relationships has led to contemporary approaches in understanding causation in the research and program evaluations especially in complex and complicated systems. One such contemporary approach in program evaluation is realist evaluation which is gaining increasing popularity in the areas of health social sciences (see also ► Chap. 20, "Evaluation Research in Public Health").

Realist evaluation is one of the theory-based approaches to program evaluation in complex and complicated systems such as healthcare systems. It was originally proposed by Pawson and Tilley (1997) who extended the Bhaskar's and other critical realists thoughts of causal mechanisms from ontological realm to an epistemic realm of human reasoning. Mechanisms, in realist evaluation, are combination of stakeholders' reasoning as well as resources offered by the social program or intervention to be evaluated. Mechanisms are activated when the program or initiative is placed in the context and they are responsible to generate outcomes. Mechanisms can be viewed as the underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest (Dalkin et al. 2015). Prime concern of realist evaluators is to understand the Context-Mechanism-Outcome configuration to address the question, "what works, for whom, under what circumstances, and how" (Wong et al. 2016, p. 1). Realist approach in research and evaluation is gaining increasing popularity in health social sciences, not only in program evaluation but also in undertaking systematic literature reviews (see ► Chaps. 45, "Meta-synthesis of Qualitative Research," and ► 46, "Conducting a Systematic Review: A Practical Guide").

4 Conclusion and Future Directions

What really is meant by “research”? What is meant by “evidence”? Why is the robustness of research claims still gauged in terms of “objectivity” and “replicability” of evidentiary claims? Why do our research questions are still directed towards answering “does it work”, instead of “how, why and for whom.”

The purpose of this chapter was not just to provide a detailed account of meaning and implications of positivism and realism as major philosophical positions, but the prime aim was to facilitate a deeper understanding of the above-stated questions which are fundamental to research in general, and health social sciences, in particular.

The chapter started with a glimpse into the history and philosophy of science, and how the organic and sense-making worldview based on meaning, faith, and reason was gradually but radically transformed into mechanistic worldview aiming for control and prediction, which further strengthened as the science progressed. This led to the birth of positivism – a theoretical position advocating for rigor and objectivity in observations, either through verification by sense-experiences or by pure logic.

While much of the quantitative research, especially in biomedical sciences, is underpinned by positivist notions in terms of emphasis on rigor, objectivity of hypotheses testing, and focus on reproducibility of the findings, qualitative research can also be underpinned by positivism if the focus is on reproducibility in terms of “what worked” instead of why and for whom. The strength of research in several areas of health social sciences, it seems, is still gauged by the generalization of evidence, where the evidence is often equated with “truth.” Generalizability of research findings, however, is increasingly being recognized as a serious issue not only in qualitative but in quantitative research as well. In medicine, for instance, it has been acknowledged that a number of ostensibly robust findings of clinical trials are not replicable, and the lack of replicability of social science research including in psychology is much prevalent (Norman 2017).

While there seems to be a consensus that lack of reproducibility may be linked to methodological factors such as statistical power, degrees of freedom, and so on, there is growing body of evidence that reproducibility might be a result of *contextual* differences or “hidden moderators,” as concluded by an analysis and recoding of 100 original studies in Psychology (Van Bavel et al. 2016).

The context-dependency of research is especially pertinent for complex systems such as healthcare systems, which are dynamic and emergent, with multiple and simultaneous causal strands, and where speculative contribution analysis rather than correlational attribution analysis provides better understanding to design and evaluate interventions (Moreau and Eady 2015).

These assertions seem to be highlighting the importance of meaningfulness, relevance, and sense-making pursuit of research (what works and form whom) rather than control and prediction. This also points to the relevance of critical realism in current social sciences and healthcare research. Through its acceptance of legitimate interpretations of reality, critical realism acknowledges the reality itself to be

stratified and emergent rather than monovalent and static. The confluence of realist ontology with constructionist epistemology facilitates a better understanding of evidentiary claims, especially for complex and dynamic environments. This is exemplified by the growing popularity of multiple or mixed-methods research paradigm in healthcare research.

To summarize, in the postmodern era, we often seem to consider positivism and realism as “unfashionable” and “orthodox.” Researchers often take pride in labelling their qualitative research as “interpretivist.” The great war between qualitative and quantitative research paradigms seems to be far from over. However, a closer inspection at the very purpose of research and its emergence as a systematic quest for knowledge provides insights on how various ontological perspectives and epistemic commitments emerged with the progress in natural and social sciences. The great war, it seems, is not between qualitative and quantitative paradigm but between the replication and meaning-making, and in very ontic distinctions of *being* and *becoming*.

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Symbolic Interactionism as a Methodological Framework

10

Michael J. Carter and Andrea Montes Alvarado

Contents

1	Introduction	170
2	The Tenets and Propositions of Symbolic Interactionism	170
3	Methodological Divergences Across the Variants of Symbolic Interactionism	172
4	Common Methods Used in Empirical Studies on Symbolic Interactionism	173
4.1	Interviews	173
4.2	Surveys	175
4.3	Ethnographies	176
4.4	Content Analysis	178
4.5	Experiments	179
5	Conclusion and Future Directions	180
	References	183

Abstract

Symbolic interactionism is theoretical perspective in sociology that addresses the manner in which society is generated and maintained through face-to-face, repeated, meaningful interactions among individuals. In this chapter, we discuss symbolic interactionism as a methodological framework. We first provide a brief summary of interactionist thought, describing the general tenets and propositions that have defined the perspective over time. Next, we discuss methods commonly employed by symbolic interactionists, noting how the interactionist perspective informs and guides sociologists in empirical research. We discuss how symbolic interactionists employ a wide variety of methods to understand both intra- and interpersonal processes, and how methodological approaches in symbolic interactionism vary in terms of their inductive or deductive style, idiographic or nomothetic causal explanation, and quantitative or qualitative research design.

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169

We address five main methods that are commonly used in symbolic interactionist studies: interviews, surveys, ethnographies, content analysis, and experiments. Future directions of the perspective are discussed.

Keywords

Symbolic interactionism · Research methods · Interviews · Surveys ·
Ethnography · Content analysis · Experiments

1 Introduction

Symbolic interactionism is a theoretical perspective in sociology that addresses the manner in which individuals create and maintain social structures (and greater society) via meaningful, symbolic communication that occurs in face-to-face encounters and in small groups. Inspired by the Scottish moralist philosophers, American pragmatist philosophers, and ideas of Charles Horton Cooley (1902, 1909) and George Herbert Mead (1934), the perspective emerged in America in the mid-twentieth century (Stryker 1980; Kuhn 1964; Blumer 1969; Carter and Fuller 2016). Symbolic interactionism is one of three main areas of inquiry and lines of research in the field of sociological social psychology (the other areas addressing *group processes* and *social structure and interaction*) (House 1977; Smith-Lovin 2001; Kelly et al. 2013; McCall 2013; Schnittker 2013). This chapter discusses the variety of methods and empirical studies that have been produced by scholars who work in the interactionist tradition.

The plan of this chapter is as follows: we first provide a brief summary of the tenets and propositions of symbolic interactionism. We then discuss basic methodological strategies that are aligned with three main variants of interactionist thought, noting how each perspective informs and guides sociologists in empirical research and how scholars use a wide variety of qualitative and quantitative methods to understand social phenomena. We then examine empirical research that has emerged over time, focusing on five main methods that are commonly used in symbolic interactionist studies: interviews, surveys, ethnographies, content analysis, and experiments. We finish with a brief discussion regarding the future of the perspective.

2 The Tenets and Propositions of Symbolic Interactionism

The term “symbolic interactionism” was coined by Herbert Blumer during his tenure at the University of Chicago, where he synthesized the work of Cooley and Mead (and others) to create a systematic framework for understanding the relationship between the individual and society. Symbolic interactionism is both a theory and method; it is particularly useful for understanding attitudes, motives, and behaviors and how individuals interpret experiences and events. It is also useful for understanding how individuals manage impressions of self and others (Goffman 1959;

Hochschild 2003 [1983]), how individuals role-play (Becker 1953; Turner 1978; Thorne 1994), how individuals cooperate and coordinate activities with others in group settings (Burke 2003; Sjöberg et al. 2003), and how individuals construct reality socially by creating shared definitions of situations (Thomas 1969 [1923]; Thomas and Thomas 1928; Berger and Luckmann 1966).

The basic tenets of symbolic interactionism are as follows: (1) individuals act based on the meanings objects have for them; (2) interaction occurs within a particular social and cultural context in which physical and social objects (persons), as well as situations, must be defined or categorized based on individual meanings; (3) meanings emerge from interactions with other individuals and with society; and (4) meanings are continuously created and recreated through interpreting processes during interaction with others (Blumer 1969).

As a perspective, symbolic interactionism developed as a reaction to the positivistic sociological theories of the day that addressed society collectively, holistically, and as a reality *sui generis* (Durkheim 1982; Parsons 2005 [1951]). At the time, the prevalent viewpoint in sociology was that external social structures and institutions impose on and constrain individuals and that any theory aimed at describing society must examine it from the “top down” by focusing on collective (macro-level) social forces rather than individual (micro-level) or social psychological processes. Blumer, who was strongly opposed to such thinking, developed symbolic interactionism as an alternative framework for understanding the social realm. Blumer’s “interactionist” perspective emphasized the need for sociologists to examine society from the “bottom up” (i.e., starting at the micro-level and moving up toward the macro-level), claiming that objective “society” and external, constraining social forces are reified in collectivistic theories. Blumer’s perspective was influenced by the work of Cooley (1927), who posited that there is no separation between self and society, that society exists only in the imagination, and that society is simply “an interweaving and interworking of mental selves” (pp. 200–201). Thus, in symbolic interactionism, “society” is conceived as the product of meaningful motives, gestures, and behaviors that occur in any given moment during individuals’ encounters with others in specific social settings. In shifting the focus from the macro- to the micro-level of analysis, Blumer’s symbolic interactionism provided sociologists with a theoretical framework that departed from over-socialized descriptions of human actors and toward an understanding of individuals as agentic, autonomous, and integral in creating their social world.

Blumer’s perspective is now known to represent the “Chicago School” of symbolic interactionist thought (Musolf 2003). Other variants of symbolic interactionism emerged after Blumer, inspired by the work of Manford Kuhn and Sheldon Stryker, whose orientations have come to be known as the “Iowa” (Kuhn 1964; Couch et al. 1986) and “Indiana” (Stryker 1980; Stryker and Vryan 2003) Schools of interactionist thought, respectively (see Carter and Fuller 2016 for a summary of the distinctions among the Chicago, Iowa, and Indiana Schools of interactionist thought).

3 Methodological Divergences Across the Variants of Symbolic Interactionism

Symbolic interactionists employ a wide variety of methods to understand both intra- and interpersonal processes. Because the areas of inquiry addressed in symbolic interactionism are so diverse, methodological approaches aligned with the perspective tend to vary in terms of inductive or deductive style, idiographic or nomothetic causal explanation, and quantitative or qualitative research design (Benzies and Allen 2001; Herman-Kinney and Vershaeve 2003; LaRossa and Reitzes 2009). Even though symbolic interactionism is known for its variety of methodological strategies, it is often framed as a *pragmatic* and *qualitative* perspective (Quin et al. 1980; Weigert 1983).

Specific methodological orientations among symbolic interactionists tend to vary depending on whether one works in the *Chicago*, *Iowa*, or *Indiana* tradition. Those aligned with the Chicago School are known to employ a phenomenological, inductive, and interpretive approach to understanding social phenomena. Bernard Meltzer's work which utilizes methods of introspection and participant observation provides a classic example of methods commonly employed by Chicago School symbolic interactionists (Reynolds and Meltzer 1973; Musolf 2008). Methods associated with the Chicago School generally represent the mainstream framework; Blumer's version is what many (if not most) sociologists think of when one mentions the term "symbolic interactionism." More empirical studies have emerged in this tradition than in any other.

Scholars aligned with the Iowa School of interactionist thought use a logical positivist and deductive approach to the study of interaction, often addressing individual or group identity processes (Herman-Kinney and Vershaeve 2003). Empirical studies in the Iowa tradition tend to use quantitative methods to understand social behavior, often relying on surveys (such as Kuhn's "Twenty Statements Test" (Kuhn and McPartland 1954)) and laboratory experiments. By taking advantage of the laboratory as a controlled environment, experimental studies in the Iowa tradition have provided researchers with the unique ability to document the process of data collection, which (some believe) leads to more certainty that research findings are valid (McPhail 1979; Katovich 1995). The production of data that can be reexamined and validated also helps address methodological critiques regarding the unreliability of qualitative research designs.

After Kuhn's death in 1963, Carl Couch and colleagues continued work in the Iowa tradition, creating what is now known as the "New Iowa School" of symbolic interactionism (Couch 1984; Katovich et al. 2003). Methodologically (and philosophically), the New Iowa School moved away from Kuhn's logical positivist orientation and toward a more pragmatist focus, addressing lived experiences and using the laboratory to observe social transactions in dyadic relationships (McPhail 1979; Katovich 1995). Whereas the Iowa School addressed the *structure* of social interaction, the New Iowa School addressed the *elements* of interaction (Herman-Kinney and Vershaeve 2003). The New Iowa School also emphasized the importance of using third-party standpoint analysis in empirical studies, which requires a

researcher to adopt the viewpoint and language of research participants when analyzing data (Diekema et al. 1996). For example, Glaser and Strauss (1964) took a third-party standpoint perspective when examining how terminal hospital patients and staff view patient conditions. They used observations to understand the awareness context of terminally ill patients (i.e., their awareness of impending death) as related to hospital staff's interactions with them, finding that staff framed their interactions with terminally ill patients with "situations of normal" interactions to shield the patient from their near death "true identity."

Sheldon Stryker (1980) and the Indiana School represent the structural symbolic interactionist perspective. Whereas Blumer's brand of symbolic interactionism views society as constantly in flux and changing from moment to moment, Stryker conceives society as stable and patterned, emphasizing the need for sociologists to consider structural conditions that exist outside the individual (Stryker 2001; Serpe and Stryker 2011). Generally, structural symbolic interactionists have more in common methodologically with the Iowa School than with the Chicago School, though those aligned with the Indiana School have used both qualitative and quantitative approaches in empirical studies (Herman-Kinney and Vershaeve 2003). Most of the research methodology aligned with structural symbolic interactionism has been developed by those who work in *identity theory* (McCall and Simmons 1978; Burke and Stets 2009; Stets and Serpe 2013) and *affect control theory* (MacKinnon 1994; Heise 2002; Robinson and Smith-Lovin 2006). Scholars working in this tradition have used participant observation (Smith-Lovin and Douglass 1992), interviews (Burke and Cast 1997), surveys (Asencio and Burke 2011; Heise and Calhan 1995), and laboratory experiments (Wiggins and Heise 1987) to understand social phenomena.

4 Common Methods Used in Empirical Studies on Symbolic Interactionism

4.1 Interviews

Interviews have long been used in social science research to learn about attitudes, beliefs, and experiences of individuals (see ► Chap. 23, "Qualitative Interviewing"). Interviews are conducted in a variety of ways, in face-to-face settings, by telephone, and recently online across digitally mediated domains. Interviews may be categorized in different ways, such as being structured or standardized, semi-structured or focused, and unstructured or unstandardized (Herman-Kinney and Vershaeve 2003; Babbie 2016; Serry and Liamputtong 2017). Interviews allow rich data collection and are useful in capturing the nuances of personal interpretation and biography, thus they are well-suited for studies that use a symbolic interactionist framework.

Examples of interactionist studies that employ interview methods include a study by McCabe et al. (2010), who interviewed 20 adult university staff (12 women and 8 men) for an average of 60 min to understand how people use traditional gender arrangements and stereotypes to frame their discussion of sexuality and sex, finding

that people's talk about sexuality at the cultural level typically corresponds to traditional gender arrangements and stereotypes. Nugus (2008) conducted 130 semi-structured interviews on clinicians to understand the way nurses and doctors in emergency rooms carve out a unique domain for their work, by interacting and negotiating with doctors and nurses from other departments within the hospital. Nugus' study also shows how symbolic interactionism can be used as reflexive criteria for validating grounded research.

In a series of studies, Burke and his colleagues (Cast et al. 1999; Burke and Stets 1999; Burke and Harrod 2005) interviewed 207 couples to understand how masculine and feminine identity meanings change during the early years of marriage. In these studies, a variety of interview techniques were employed, including 90 min face-to-face interviews with married couples, having couples keep weekly diaries, and having couples videotape themselves while resolving an issue.

In the field of environmental sociology, Pennartz (1989) conducted interviews with households from different neighborhoods to understand their views of the environment and their opinion of inner cities. Pennartz used these interviews to identify the codes and values that operate within the consumption and production of the urban environment and to describe the function of urban elements as a potential counterbalance against the colonization processes of the lifeworld.

Symbolic interactionist studies that use interviews vary in terms of sample size, with some researchers interviewing only a few participants. For example, Day (1985) showed how symbolic interactionism is relevant for social workers in a study that analyzed interviews involving a single social worker, a client, and a team leader. In noting the different views of the people involved in the study, Day showed that it is necessary to take into account the organizational context of interviews. He noted that the interview process involves interpretation and the social construction of reality, which has implications for any study that uses interviews to collect data.

In a study that interviewed seven participants, Barton and Hardesty (2010) examined how exotic dancers define their experience of stripping and how dancers use the language of "spirituality" as a narrative resource. They found that exotic dancing is often a multifaceted experience for women and that strip bars are a more-nuanced environment than most realize. In defining dancing as a spiritual act, exotic dancers deflect the popular understanding of strip clubs. By constructing exotic dancing as a spiritual activity, stripping then becomes an unexpected and welcome source of inner power.

A final example of an interview study that uses a small sample size is provided by Curry (1993), who interviewed a single person in his study on pain and injury. By focusing on one participant named Sam who was an amateur wrestler, Curry showed how the perception of experiencing pain associated with a sport can change over time. For Sam in the early years of his career, pain and injuries were something to be ignored and endured as a test of masculinity. Over time his attitude about pain and injuries changed to be the forefront of concern and something to be avoided, as they are direct hindrances from success in one's sport. By intensely interviewing a sole participant, Curry provided a detailed account that illustrates the nature of the changing self.

4.2 Surveys

Surveys are perhaps the most common research method used in the social sciences; many studies in the interactionist tradition use some type of survey design. Surveys are appropriate for descriptive, exploratory, and explanatory research. They are especially useful for collecting data from large samples and for measuring common social psychological processes such as attitudes and beliefs. They also are useful for measuring a wide variety of demographic and psychometric variables in a short amount of time. Survey questionnaires can include closed-ended response categories, which often provide quantitative data that is conducive for statistical analysis, or open-ended questions that are appropriate for qualitative data analysis. Many surveys also have the advantage of being self-administered and thus do not have the logistical difficulties that often plague face-to-face interviews or laboratory experiments (see ► [Chaps. 32, “Traditional Survey and Questionnaire Platforms,”](#) and ► [76, “Web-Based Survey Methodology”](#)).

Kuhn and McPartland’s (1954) “Twenty Statements Test” (TST) (mentioned previously) is a classic example of a survey measure commonly used by symbolic interactionists. The TST is used to measure the self-concept. Known for its simplicity and ease of use, participants who receive the “test” are given a sheet of paper with the words “Who am I?” written at the top, with twenty blank lines listed below. Participants then fill in each line according to who they see themselves as (e.g., possible answers might be “a student,” “a friend,” etc.). Many studies have employed some variant of the TST over the past decades (Franklin and Kohout 1971; Grace and Kramer 2002).

Another example of past survey research in the interactionist tradition is provided by Burke and Tully (1977), who used semantic differential scales to measure gender role identities in school children. Students were given the survey and asked to respond to statements such as “usually boys are. . .” or “usually girls are. . .,” and “as a boy (or girl) I usually am. . .” In their analysis, they found that gender role identities were unimodal and normally distributed for most participants in their sample but that approximately one-fifth of the sample had gender identities that were more aligned with the modal identity for the *opposite* sex than that of their own sex. Burke and Tully’s study was groundbreaking, providing symbolic interactionists with a method for measuring identity meanings that is used to this day.

Vignettes are also commonly used by symbolic interactionists in survey designs. For example, Stets and Carter (2006, 2012) measured moral behavior by asking participants to report on how they behaved in past situations such as finding a lost wallet, having an opportunity to cheat on a test, or having an opportunity to give money to a homeless person. Reid et al. (2015) examined the importance of “setting” as a factor in shaping college students’ dating and sexual behavior. They explored how students interpreted a vignette describing a casual heterosexual encounter at a party followed by a sexless dinner date, finding that rather than simply following generalized cultural scripts, heterosexual encounters of college students are guided by standardized patterns of behaviors based on the distinct settings and roles

associated with each situation. A study conducted by Carter and Mireles (2016a, b) used a vignette design and administered a survey questionnaire to deaf and hard-of-hearing individuals to measure how deaf identity processes and attachment to the deaf community correlates with self-esteem and depression.

Analysis of secondary survey data is another method that is sometimes used by symbolic interactionists. For example, McPherson et al. (2006) compared the 1985 and 2004 General Social Surveys (GSS) to see if individuals' degree of closeness to other members in their social network had changed over time, showing that people had become more socially isolated over a two-decade timespan. Whether taking the form of a self-administered questionnaire or secondary data, surveys are one of the most common methods used in symbolic interactionist studies.

4.3 Ethnographies

An ethnography is a (mostly) qualitative research method that attempts to systematically investigate and then accurately represent some form of culture using an emic (i.e., “inside-out”) perspective to understand social phenomena, compared to other methods (such as surveys and experiments) that generally use an etic (i.e., “outside-in”) perspective. While etic approaches examine social phenomena in a detached manner, ethnographies seek to understand a culture on its own terms and from the perspective of those individuals within it (Scott and Garner 2013; see ► Chap. 26, “Ethnographic Method”). Symbolic interactionists are often interested in subcultures, small group norms and behavior, and role-playing. Ethnographies allow for rich descriptions of all such phenomena, so they are appealing to and commonly used by many symbolic interactionists.

In practice, “ethnography” is an umbrella term that represents a variety of research strategies (Berg and Lune 2012). Some ethnographies involve field studies or written accounts of observations (Ellen 1984; Stoddart 1986). Some involve active participant observations of a social setting (Warren and Karner 2005). Others see ethnographies as detailed descriptions of natural settings that offer no explanations (Babbie 2016). And, those who use autoethnography as a research method use their own personal experience as a basis for scholarly knowledge (Ellis and Bochner 2000; Carter 2016). Regardless of the “type” of ethnography one practices, all tend to value *depth* over *breadth* regarding data collection – data take the form of rich descriptions of events. Ethnographies are thus often considered strong on validity but weak on reliability, as some doubt the efficacy of using ethnographic data for generalizing to greater populations or generating abstract theories. Regardless, some of the most well-known and respected studies in the interactionist tradition use ethnographic methods.

Gary Alan Fine is a prominent symbolic interactionist who has used ethnographies to understand subgroup cultures and the nature of everyday social life. In *Kitchens*, Fine (1996) conducted an ethnography to understand the culture of restaurant work, showing how working conditions, time constraints, market forces, and aesthetic goals all combine to affect food that is served to customers. Fine has

also used ethnographic methods to study the culture of mushrooming (Fine 1998), high school debate teams and adolescent culture (Fine 2001), and even the world of competitive chess (Fine 2015).

Robert Park, a famous sociologist from the University of Chicago said that understanding human behavior requires researchers to immerse themselves in the worlds of their subjects – to study individuals in their own terms in order to understand the symbolic meanings that those individuals themselves define as important and real (Herman-Kinney and Vershaeve 2003). Participant observation is an ethnographic field method aimed at capturing such phenomena. It is used to study small groups and homogeneous cultures. In a participant observation, ethnographers immerse themselves in a society, often living with (or spending an extended time with) the group under study, participating in daily activities and carefully observing experiences (Tedlock 2005). Data produced by participant observation are generally rich with detail and description; hence the information gathered using the method is considered to accurately reflect the views of those native to a specific group or society (Tedlock 2005).

Symbolic interactionists have long relied on participant observations to better understand the nature of social life and subcultures. As a method, it is particularly well-suited for the perspective, as it seeks to identify and understand the creation and maintenance of meanings that actors use to navigate their everyday lives. Classic participant observation studies include Liebow's (1967) *Tilly's Corner*, which documents his participation and observation of black men who spent time together on a street corner. In *Boys in White*, Becker et al. (2009 [1961]) observed young men who aspired to become physicians, documenting the difficulty of their journey toward becoming a doctor and how medical students feel about their training and the profession they will one day enter. *The Urban Villagers* portrays Herbert Gans' (1962) observations when he moved to an Italian enclave in Boston in order to immerse himself in the community and gain a better understanding of the lives of local inhabitants.

In more current research, Gottschalk (2010) used participant observation to understand how interactions in virtual spaces shape everyday life in the digital age. By participating in the virtual world *Second Life*, he documented how digitally mediated environments are both social psychological playgrounds where participants enjoy individualistic fantasies as well as virtual communities where individuals collaborate on collective projects. Rafalow and Adams (2016) observed encounters in bar settings and how patrons' use of digital communication technologies both augment the bar experience and shape social networks that may develop through interactions in such places. Harvey (2017) observed volunteers who worked to rebuild New Orleans after Hurricane Katrina, specifically the cultural performance and symbolic exchange of food among those involved in the rebuilding. She found that food was used as a way to welcome and compensate volunteers for their hard work and to celebrate progress in rebuilding the community but that over time the giving and consuming of food was renegotiated. Regardless of form, some of the most influential and recognized studies in the interactionist tradition use ethnographic methods.

4.4 Content Analysis

Content analysis is a detailed examination and interpretation of some (usually) material source that is aimed at revealing patterns, themes, and meanings that are embedded within such sources (Berg and Lune 2012; see ► Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility”). Content analysis can be inductive or deductive. Inductive approaches are used in cases where no previous studies exist regarding a phenomenon (or when the understanding of a phenomenon is fragmented or unclear); deductive approaches are useful when the general aim is to test an existing theory or compare categories at different time periods (Elo and Kyngas 2007). Content analyses are common in symbolic interactionist research. They are also prevalent in health sciences, particularly in nursing studies (Elo and Kyngas 2007). Content analysis is an umbrella term that represents a wide variety of research methods, such as textual analysis, life history analysis and biographical methods, document analysis, conversation analysis, and the study of semiotics and signs (Herman-Kinney and Vershaeve 2003).

Perhaps the most famous content analysis study in the realm of symbolic interactionism is Thomas and Znaniecki’s (1996) *The Polish Peasant*. In this study, the letters and diaries of Polish immigrants living in Chicago were analyzed to understand the nuances of immigrant life and the trials and tribulations of living in a different culture away from one’s homeland. Other classic examples are provided by Jacobs (1967), who examined letters left by those who committed suicide, and Molotch and Boden’s (1985) study of the Watergate congressional hearings, which used conversation analysis as a method to determine how power was negotiated among those involved in the political scandal. Denzin (1987) demonstrated the benefit of using semiotics (the study of signs, symbols, and the systems that create them) and symbolic interactionism together in his analysis of narrative texts of advertisements for Jack Daniel’s Whiskey and Dewar’s White Label Scotch to understand the political economy of signs.

In more recent research, Silva (2014) used frame analysis (Goffman 1974) to examine how anti-evolutionists neutralized the framing of their position as religious by analyzing 570 letters published in American newspapers in the months surrounding a nationally covered federal judicial decision on the legality of a school’s decision to undermine evolutionary theory in a classroom. Silva showed that anti-evolutionists neutralized the framing of their position as religious through the processes of selective acknowledgement and disagreement with the problematic framing.

In her article “I am a Cheerleader, but Secretly I Deal Drugs: Authenticity through Concealment and Disclosure,” Smirnova (2016) performed a content and discourse analysis of 1600 submissions to the PostSecret mail-art project and revealed how secrets are used to manage disparate social, role, and personal identities. She found that people attempt to maintain or achieve authenticity through dialectical acts of concealment and disclosure, showing that individuals keep and disclose secrets in order to maintain authenticity contextually within relationships, as well as across contexts through self-reflexive evaluations.

Other contemporary examples of content analyses includes a study by Sawicka (2016) that analyzed discussion lists for bereaved parents to understand how they collectively managed the grief that emerged due to their experience of perinatal loss/stillbirth. And, Cross (2015) analyzed magazine columns, letters, memoirs, and first person essays to discover how people form attachments to geographic locations (i.e., places), proposing that seven distinct processes interact at the individual, group, and cultural level to shape how individuals form attachments to specific places.

4.5 Experiments

While they are common in psychology, experimental methods (especially laboratory experiments) are less common in sociology. Thus, overall, symbolic interactionist studies that rely on experimental methodology are less common compared to studies that use participant observation, surveys, or interviews as methods of inquiry. However, those who work in the interactionist tradition and use experiments note the strength of the method, largely because the perspective seeks to understand social psychological processes that are often conducive for study using experimental designs.

A benefit of experiments is that they are well-suited for theory testing. Laboratory experiments offer scholars the ability to control a social environment and place subjects in a setting where stimuli can be manipulated to determine cause and effect. Some scholars use the traditional experimental design by randomly assigning subjects into experimental and control groups, pretesting each group at time 1, introducing an independent variable to the experimental group, and then posttesting both groups at time 2 to compare the effect of the independent variable. Others employ quasi-experimental designs (such as field experiments) that resemble but deviate from the traditional design in some way (see ► Chaps. 36, “Eliciting Preferences from Choices: Discrete Choice Experiments,” and ► 37, “Randomized Controlled Trials”).

Classic experimental studies in symbolic interactionism were conducted by those associated with the Iowa School of interactionist thought (Couch et al. 1986; Couch 1987). Notable experiments during this era (and after) include Haney et al.’s study of prison life (Haney et al. 1973), Darley and Batson’s (1976) study on helping behavior, and Goldstein and Arms’ (1971) study of aggression. A more recent example of symbolic interactionist studies that employ experimental designs is provided by scholars who work in identity theory (Stryker and Burke 2000; Burke and Stets 2009). Scholars who work in identity theory have used experiments to better understand how identities motivate behavior and how social structural conditions combine with identity processes to impact behavior. For example, in a study on morality, Stets and Carter (2011) used an experimental design that placed study participants in a laboratory setting where they had the opportunity to cheat to gain an advantage over others, revealing that cheating behavior is predicted depending on the meanings of one’s moral identity. In related research, Carter (2013) brought participants to a laboratory and manipulated moral identity activation and different group conditions to discover how activated identities and social context influence moral behavior in situations where people are awarded more than they deserve for completing a task.

In other research, Katovich (1987) conducted a laboratory study (systemic observation) of 24 dyads that were given either a role-playing identity as a manager or potential employee and found a linking process of interpersonal situated identities and broader future-oriented concerns. Pechmann et al. (2010) used symbolic interactionist theory and conducted three experiments to examine how altering the age of models used in cigarette advertising affects whether adolescents are drawn to or deterred from smoking. They found that adolescents exhibited a boomerang effect when exposed to teen cigarette models, lowering the intent to smoke, while exposure to young adult cigarette models increased the intent to smoke.

Like all methods, experiments have both strengths and weaknesses. Some scholars who work in the symbolic interactionist tradition question the efficacy of using laboratory experiments to study micro-level social phenomena, claiming that lab settings are contrived, artificial environments that are unlike normal life experiences. Proponents of experimental methods claim that while lab settings may be unique, they aren't necessarily so distinct and removed from real experience that they offer no utility for the study of human behavior. While scholars who work in different traditions of interactionist thought may disagree on the utility of experimental methodology, there are a variety of influential studies aligned with the perspective that have used experimental designs.

5 Conclusion and Future Directions

Symbolic interactionism is approaching its centennial as a distinct theoretical perspective and method. The glut of extant interactionist studies and its continued popularity shows that it is – *de rigueur* – a leading theoretical perspective in sociology and across the social sciences. Ironically, in the past some have predicted that the perspective might wither and fade over time as a distinct sociological paradigm, as the concepts that once were unique to the perspective become more integrated into mainstream sociology (Sandstrom and Fine 2003). If the “future” is “now,” it seems safe to say that such a decline has not occurred, as evidenced by the wide variety of published empirical research that continues to be aligned with symbolic interactionism. Since the framework seems to be flourishing, let us consider its future trajectory regarding research methods and epistemological strategies.

Fifteen years ago, Sandstrom and Fine (2003) predicted that in the future, symbolic interactionism would become more characterized by theoretical and methodological diversity and that the methodological differences among those in the Chicago and Iowa/Indiana traditions would begin to diminish. They also predicted that symbolic interactionists would begin to address macro-level concepts and analyze relationships among large-scale social entities. Regarding the first prediction, it seems accurate to claim that contemporary symbolic interactionists tend not to identify the school of thought that directs their study, but the common methodology likened to each school of thought is still evident in specific studies. Regarding the second prediction, a review of the recent literature reveals that studies that address macro-level or large-scale phenomena are still by far the exception rather

than the rule. There are interactionist studies that address abstract or aggregate processes (Dennis and Martin 2005; Salvini 2010), but even these studies are more rooted in micro-level processes than social forces that are commonly understood to represent the macro realm. So, it seems that methodological approaches and units of analysis addressed in symbolic interactionist studies are similar to what they have been in the past. From our perspective, this is not surprising, as the perspective was originally conceived to explain micro-level phenomena, and scholars continue to find new areas of study at this level of analysis.

Regarding the future of research methods *per se*, it seems unlikely that studies conducted in the interactionist tradition will deviate much from the variety of methods described in this chapter. Interviews, surveys, ethnographies, content analyses, and experiments will continue to be methods commonly employed by symbolic interactionists (perhaps some more than others). However, these methods will evolve and will continue to be shaped by advances in technology as scholars find new ways to improve research designs and the process of data collection. Any scholar who has followed the development of symbolic interactionism over the decades has witnessed such change. For example, in only the recent past (going back 20 years or so), surveys usually took a physical form; hard copies of questionnaires were often disseminated in person or mailed to participants and then collected after completion. Response data then had to be manually entered into a computer to be analyzed (or in the distant past, analyzed by hand), often taking a team of researchers and a great deal of time. With advances in electronic technology and the creation of the Internet, surveys are now often administered via digitally mediated forums. Indeed, online surveys might now be the norm rather than the exception. Electronic survey platforms allow for quick data collection, and they eliminate the need for data entry, allowing researchers to analyze data virtually the moment they are gathered. Of course, new issues regarding reliability and validity of data collection accompany such advanced technology. Research methods in the social sciences are in a constant process of revision and refinement.

A specific example of how technology has improved survey research methods regards the experiential sampling method (ESM) (Hektner et al. 2007). ESM is aimed at measuring moment-to-moment experiences and the quality of everyday life, themes that are of central interest to symbolic interactionists. Studies using this method typically select participants and then have them respond to questions that are given to them at varying times throughout the day, during their usual routines, interactions, and encounters. For instance, an ESM study might be conducted to understand how individuals' moods and emotions change from moment to moment. Periodically, throughout the day, participants in such a study would be prompted to report their current mood state. After data are collected, a researcher can see how moods change for each participant, and a variety of analyses can be performed on the collected data. The ESM method is beneficial because it does not rely on memory recollection or past accounts of experiences, things that are commonly understood to plague survey questionnaires.

ESM methods have developed considerably with advancements in technology. Early ESM studies involved participants carrying watches or pagers that would beep

or vibrate, prompting participants to stop what they were doing and answer a paper-and-pencil survey. Later studies used personal data assistant (PDA) devices (such as Palm Pilots) that allowed for responses to be recorded electronically. The advanced technology available today has greatly improved the accuracy of ESM data collection, as data can be collected in real time on apps via smartphones. These newer technologies have reduced costs and helped to eliminate logistical issues associated with ESM studies. Such strategies will likely continue to improve in the future as technology continues to improve. Methods like the ESM are especially dependent on technology. As technology continues to evolve, more and more sophisticated techniques will be used to gather data instantaneously from study participants.

Advanced technology has improved experimental methods as well. In the past, experimentalists relied on devices such as two-way mirrors for surveillance of participants in laboratories. Now experimental researchers use more sophisticated forms of surveillance, with hidden camera technology and a wide variety of instruments available that record subtle behaviors and various social processes. For example, continuing the example of studying emotions, experimentalists who study emotions have developed sophisticated technologies capable of measuring affective responses. Laboratory research documenting the relationship between emotion and brain activity has used functional magnetic resonance imaging (fMRI), electroencephalography, and infrared thermography to measure emotional reactions (Clay-Warner and Robinson 2015). As these and other technologies continue to improve, researchers who conduct experiments will have even more precise mechanisms available to study human behavior in laboratory environments. The above examples illustrate how technology continues to improve research methods used by symbolic interactionists.

The future of the symbolic interactionism seems bright, as evident by the continued interest and development of the field. As noted by the *Society for the Study of Symbolic Interaction* (SSSI) (<https://sites.google.com/site/sssiinteraction/>), many subdisciplines within the social sciences have been influenced by symbolic interactionism, including the sociology of emotions, criminology, collective behavior and social movements, feminist studies, social psychology, communications theory, semiotics, education, nursing, mass media, organizations, and the study of social problems. In this chapter, we have discussed the variety of research methods employed by scholars who work with or align themselves with the interactionist tradition. While we have addressed many common methods that have come to define the field, our coverage is by no means exhaustive. The myriad approaches and examples of interactionist methods that have appeared in empirical studies cannot be adequately summarized in one chapter (e.g., some consider work in ethnomethodology (Garfinkel 1967) to be aligned with symbolic interactionism; we do not address this work here). As long as social scientists remain interested in micro-level social phenomena and the relationship between the self and society, symbolic interactionism will continue to hold a place among the most influential sociological paradigms. And, as the field grows in numbers and more empirical studies emerge, the research methodology associated with symbolic interactionism will continue to develop and improve.

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Hermeneutics: A Boon for Cross-Disciplinary Research

11

Suzanne D'Souza

Contents

1	Introduction	190
1.1	Bracket or Not to Bracket?	190
1.2	Hermeneutic Influences in Research	191
1.3	The Current Neglect of Hermeneutics	191
2	The Main Tenets of Hermeneutics	193
2.1	The Question of Being	193
2.2	The Thereness of Being	193
2.3	Being and Becoming	194
2.4	Being in the World of Care	195
2.5	Space and Time	195
2.6	Verstehen	196
2.7	The Hermeneutic Circle	197
2.8	Language: The House of Being	197
3	Hermeneutics: The Springboard to Cross-Disciplinary Research	198
3.1	Addressing Complex Phenomena	199
3.2	Adding Depth and Breadth	200
3.3	Providing a Selection of Interpretive Methods	200
4	Conclusion and Future Directions	201
	References	202

Abstract

Hermeneutics has long been used with huge gains in various fields of research as the underpinning paradigm. In particular, Heidegger's interpretive framework of being and becoming has influenced many a research undertaking owing to its resilience and flexibility in bringing to life the lived experience. However, despite its versatility, hermeneutics is largely overlooked in current research contexts

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189

because of its density of ideas and verbosity. Hence, the aim of this chapter is to unpack the main tenets of Heideggerian phenomenology as embodied in *Being and Time* and make a pioneering effort to underline the implications of such a framework for cross-disciplinary research. Heidegger's facticity of being is first explicated followed by an overview of the thereness of being which comprises being in the world of care spatially and temporally. In this existential state, *verstehen* or understanding is an event that occurs when the three fore-closures of the hermeneutic circle – fore-having, fore-sight, and fore-conception, work collaboratively to foreground meaning. Interestingly, in this ontological circle, it is language that serves as the medium of understanding. The benefits this ontic approach offers researchers, notably, those interested in cross-disciplinary research, are manifold. The main elements of hermeneutics provide a unique, flexible framework to examine a range of complexities and open up rich avenues for a multidimensional enquiry. Hermeneutics is indeed a boon for cross-disciplinary research. Harnessing the rich potential of hermeneutics would credit researchers with a sound intellectual base, advance cross-disciplinary research, and optimize the quality of research outcomes.

Keywords

Heidegger · Hermeneutics · Ontology · Being · Becoming · Cross-disciplinary research

1 Introduction

Hermeneutics, a branch of phenomenology, has long been used with huge gains in various fields of research as the underpinning paradigm. In particular, Heidegger's interpretive framework of being and becoming, commonly referred to as interpretive phenomenology, has been influential in shaping research undertakings, owing to its resilience and flexibility in bringing to life the lived experience. Derived from a Greek word, *hermeneuein*, the term hermeneutics means the study of methods of interpretation, primarily associated with the interpretation of the Bible and other texts (Cammell 2015). Thus, Heideggerian hermeneutics is closely connected to interpretation and signals a transition from epistemology to ontology: from the concept of understanding as a mode of knowledge to a study of being.

1.1 Bracket or Not to Bracket?

Heidegger's predecessors, Husserl and Dilthey, posited that understanding the essence of human existence is a hermeneutic act that entails a study of the life world of human beings. Husserl and Dilthey privileged the subjective meaning that humans accord to the lived experience, over preconceived ideas linked to the experience, and suggested that setting aside or *bracketing* these ideas would help unveil the meaning of the lived experience (McConnell-Henry et al. 2009;

Ortiz 2009; see also ► Chap. 112, “Understanding Sexuality and Disability: Using Interpretive Hermeneutic Phenomenological Approaches”). However, Heidegger’s strand of hermeneutics departed from these phenomenologists, in that he set much store on prior knowledge. Heidegger subscribed to the view that meaning lies latent in every situation. It is only by applying prior knowledge or the subject’s world view to the situation that implicit meaning is manifested to concrete meaning (Steiner 1978; Dowling 2004). His thesis is that language is the basis for both experiencing and understanding the world (Powell 2013). The capacity to understand events in the *life world* through language, by ascribing meaning to social situations, has rendered Heideggerian hermeneutics a powerful, intellectual trajectory.

1.2 Hermeneutic Influences in Research

Given its adaptability to diverse research situations and its pliancy in bringing to life the lived experience, Heidegger’s interpretive framework has influenced a sizeable amount of research in various fields, specifically health and social sciences. In the context of health, Benner (1984) has used it successfully to study the lived experience of nurses when delivering care in Australian hospital settings. In the United Kingdom, Koch (1994) employed a hermeneutic approach to investigate the relationships between elderly patients and nurses during hospitalization. There are also several hermeneutic studies in critical care (Walters 1995; Little 2000; Johnson et al. 2006), mental health (Aho 2008; Kayali and Furhan 2013), and pediatrics (Totka 1996; Sorlie et al. 2003; Olausson et al. 2006). In the field of social science, Ream and Ream (2005) drew on hermeneutics to analyze the meaning of student dwelling in learning environments, while Greatrex-White (2007) explored the experiences of nursing students studying overseas. Hermeneutic enquiry has also been conducted to analyze teacher-student relationships (Giles et al. 2012), the nature of teaching and learning (Horrocks 2006; Vu and Dall’Alba 2008; Peters 2009; Riley 2011; Jones 2011), educational programs and their emphasis on the becoming of students (Ironside 2003; Dall’Alba 2009), and curriculum development (Donnelly 2002; Slattery et al. 2007; Gibbons 2011). Nevertheless, despite its resounding success as a philosophic base, interpretive phenomenology is largely overlooked by new researchers and doctoral students.

1.3 The Current Neglect of Hermeneutics

There are three main causative factors for the current neglect of hermeneutics. Firstly, Heidegger’s ideas, as expounded in *Being and Time*, his main body of work, appear to be “esoteric and forbidding” (Cammell 2015, p. 236) and considerably complex to the average reader (Schmitt 2008; Peters 2009). Moreover, according to Smith (2009), after navigating the difficult terrain of Heidegger’s

interpretive phenomenology, readers are left disgruntled and unsated since Heidegger fails to offer answers to the questions he raises. The evidence provided indicates that emerging researchers and doctoral students new to the research process could be discouraged by the density of Heidegger's ideas, the verbosity with which he expresses them, and their own frustration at being abandoned at the brink of being. This situation is further exacerbated by the use of certain German words that defy English translation. Another related issue is the opacity of Heidegger's ontology (Schmitt 2008; Peters 2009). To most readers, Heidegger's obsession with ontology, the study of existence, comes across as absurd and illogical, as it dwells on an abstract question – *What does it mean to be?* We take it for granted that we know what it means to physically live in the world; as such, Heidegger's emphasis on the state of *being* in the world, a vague, unsubstantial notion confounds readers. Consequently, lack of knowledge on how to relate seemingly abstract hermeneutic concepts to concrete aspects of their research deters researchers from utilizing hermeneutics as the overarching paradigm to conceptualize their study.

Additionally, the fear of misinterpreting Heidegger's philosophy also sparks methodological concerns among researchers. The bulk of hermeneutics converges upon the study of lived experience which serves as a reservoir to help people interpret and make sense of life (Huang et al. 2012; Guenther 2012; Spratling 2013). Phenomenologists view interviews as one of the primary data collection methods as respondents are able to provide a subjective account of the experience encountered from which meaning can be distilled (DePoy 2016; see also ► Chap. 23, "Qualitative Interviewing"). However, Paley (2014) argues that focusing on the subjective meaning of the lived experience is a misinterpretation of hermeneutics. While Paley acknowledges that human beings have a number of experiences in the world, he states that the interpretive stance on lived experience is misconstrued to include a separate layer of experience, the subjective experience, "a ghostly, subjective thing, allegedly going on at the same time" (p. 4) as the lived experience. In effect, there is no such thing as subjective experience to recall or understand because human beings find meaning in life by interacting with things around them and "get on with stuff" (p. 5). Indeed, Paley opines that interviewing is not an interpretive strategy and claims there is nothing to gain from interviews for respondents merely fabricate answers to questions. His conclusion is that phenomenological researchers should carefully consider their research design, avoid qualitative interviews, and seek other methods of enquiry.

Viewed in the light of the evidence presented by Paley (2014), it is evident that misinterpretations of Heidegger's philosophy are entirely possible. Added to this, the fear of selecting methods of enquiry incongruent with hermeneutics, which would in turn affect the trustworthiness of their study, steers doctoral students and new researchers away from hermeneutics. Being a doctoral student and a cross-disciplinary researcher, I have found myself in the same predicament: questioning the validity of interpretivism to my study, grappling with the fear of misinterpreting hermeneutics, and misapplying the philosophy. Eventually, after an in-depth study of hermeneutics, I concluded that the benefits of hermeneutics lie in the reading or – should I say – interpretation! This chapter emerged as a result of my extensive

reading of hermeneutic literature in an attempt to motivate and encourage fellow researchers to pursue the less tread but most valuable path of hermeneutics. Therefore, the aim of this chapter is to unpack the main tenets of Heideggerian phenomenology, as embodied in *Being and Time*, Heidegger's monumental work, and underline the implications of such a framework for cross-disciplinary research. How to use the evidence presented here to conceptualize your cross-disciplinary study, I leave to your interpretation!

2 The Main Tenets of Hermeneutics

2.1 The Question of Being

The fulcrum of interpretive phenomenology is the essence of being. What is being? Bonevac (2014) points out that the meaning of being is “self-evident, primitive, obvious or impossible to articulate. After all, everything’s doing it, all the time!” (p. 166–167). However, Heidegger elevates the meaning of being to a transcendental level: *A being is*. This response sets out being as a vague entity, for the verb “is” in the process of being is unknown. It is not possible to explain the “is” in explicit terms; yet, rich, concrete meaning is hidden within the verb (Heidegger 1978). The paradoxical characteristic of being, its tendency to be abstract and tangible at the same time, urges Heidegger to pronounce it as the poorest and the richest of concepts. It is the poorest concept because *to be*, the act of existence, is an empty, meaningless notion. On the other hand, the fact remains that beings exist and have existed since the dawn of time. If beings exist, they are not nullity – they are something, with their own rich characteristics of being. Consequently, the act of being is rich in meaning, making it a valuable concept. Cammell (2015) elaborates that beings are already a part of the world, with their own distinctive traits. They dwell in language and move along the tangent of time with a prior understanding of how to do things: birthing and raising children, forging relationships, overcoming failure, and eventually facing death. Thus, the meaningless act of being becomes rich in significance when interpreted against the backdrop of the many phases of life and the meaningful relations that beings enact with one another (Campbell 2012). In this way, Heidegger sought to move hermeneutics from the level of epistemology (a passive, cognitive understanding of a phenomenon) to ontology (an active understanding of the phenomenon by interpreting the fullness of being in the world). It is this ontic question of being that Heidegger is engrossed with, and to which I turn, to explain the *thereness* of being in the world.

2.2 The Thereness of Being

Interpretive phenomenology revolves around *Dasein* or being. *Dasein* is defined as “an entity whose Being has the determinate character of existence” (Heidegger 1978, p. 34). *Dasein*, a German word for human being, constitutes two parts: *da* referring

to here or there and *sein* meaning to be or being. The two word meanings underline the ontic nature of hermeneutics – to live is to be, since existence requires human beings to be out there in the fullness of the world (Dowling 2004; Greaves 2010). According to Heidegger (1962), the world is a sort of a thing that *Dasein* dwell in. It comprises a holistic web of interrelated beings, both animate and inanimate. Bonevac (2014) notes that Heideggerian hermeneutics underlines the social nature of *being in the world*. Thus, Bonevac (2014, p. 170) maintains that “we are not, of course, alone in the world. We encounter other people, other selves, other *Daseins*,” and when cast into the *thereness* of the world, *Dasein* or human beings forge relationships with other entities as they engage in the *everydayness* of living. They do this by drawing on the varied action possibilities present in the world to actively participate in and sustain life. In fact, *Dasein* share a symbiotic relationship with other beings, for, in the course of completing practical tasks, *Dasein* support and nurture one another (Heidegger 1962, 1978; Steiner 1978; Koch 1994; Dall’Alba 2009). Heidegger’s allusion to the reciprocal nature of existence reinforces the idea that we are always there in the world in some way or the other and we use the *equipment* or entities we encounter to function in the world. All equipment are *ready-at-hand*, in order to complete a specific task. For instance, a pen for writing and a knife for cutting are *ready-at-hand* equipment with distinctive uses. Bonevac (2014, p. 169) contends that “their being consists of their handiness,” being *ready-at-hand*. In the same way, *Dasein* have a particular purpose in life that is fulfilled by immersing themselves in the *thereness* of the world by engaged involvement with other members of the community (Greaves 2010). In the course of each engaged encounter, beings perceive their own identity in relation to other beings which makes transparent the meaning of life. Hence, shared practices and common meanings are essential to the unveiling of *Dasein*.

2.3 Being and Becoming

Heidegger pursues the idea of an individuals’ capacity to become, by maximizing the potential to be. Heidegger (1962, 1978) emphasizes that the potential to be lies dormant in every being. Bonevac (2014, p. 172) writes: “As *Dasein*, I face a field of possibilities. I am located within such a field, and my location determines the possibilities that are alive for me.” Heidegger (1962, 1978) reports that individuals could either be wakeful to their being and achieve optimal outcomes in life or be slumberous and let life pass by. Wakefulness to the call of being denotes active engagement in shared practices, *being with* and *being amidst* others, and apprehending the meaning of lived experiences. It is possible to apprehend the totality of life when we realize that a gap exists between the actuality (living a routine, pedestrian life) and possibility (the ability to maximize our potential) of being that prevents us from *becoming* who we are. Understanding the gap between our current state of being (merely existing) and our infinite potential to be (the capacity to live life to the fullest and achieve positive outcomes) paves the way for our *becoming* as human beings (Heidegger 1962, 1978).

Bonevac (2014) elaborates on Heidegger's theory of being and becoming by explaining that being in the world, that is, *being with* and *being amidst* others, opens up a field of possibilities for *Dasein* to use. Journeying toward the future by fully interacting with other beings, making wise choices, and converting probabilities into possibilities is being fully awake to *Dasein's* being. *Dasein* can raise themselves from being to becoming, from probability to possibility, by operating fully within their realm of possibilities, understanding themselves and the world they live in. In short, being wakeful to the purpose of life bestows on us the meaning of existence.

2.4 Being in the World of Care

Wakefulness to *Dasein's* being, a hermeneutic trait, draws attention to Heidegger's notion of care (*sorge*) and its connection to existentialism. Heidegger (1978) holds that care is a benevolent quality that enhances a being's selflessness. It can only be administered when beings negotiate meaning by interacting with other entities present within the world. Heidegger elaborates on two approaches to care: care as day-to-day worries (interventionist care) and care as concern or wakefulness to *Dasein's* being (emancipatory care). While the former approach is a mundane, everyday aspect of existentialism, it is the latter that elevates beings to acts of concern for others. It prompts beings to rise above themselves and learn to cope with situations by assuming a sense of responsibility and displaying sensitivity toward the needs of others (Joensuu 2012; Larivee 2014). Additionally, Heidegger maps caring on a continuum with interventionist and emancipatory care on either end. Interventionist care focuses on alleviating the anxieties of entities by arbitrating on their behalf or *leaping in* for them, as in the case of a nurse caring for a sick child or a parent looking after a child. In contrast, emancipatory care is concerned with *leaping ahead* or empowering someone with the skill to take care of themselves. It channels beings toward maximizing their future potential, and *Dasein* should aim for emancipatory care that bestows independence (Tomkins and Eatough 2013). Thus, *sorge* is critical for conducting meaningful interactions between beings in the world.

2.5 Space and Time

Being in the world also constitutes being in the world spatially and temporally. Time and space are intertwined elements in which *Dasein* dwell. Heidegger (1978) uses the terms dwelling and spatiality interchangeably. Dwelling in a house has little relation to occupying space, instead it denotes a sense of belonging; so too, human beings belong to this world and their belonging is manifested through their temporality. It is important to note that in this intellectual orientation, space and time are not perceived as measurable items; rather, emphasis is given to being in a particular place at a specific time. With regard to spatiality, Heidegger (1978) reiterates that the process of existentialism has granted human beings a predestined place in the world. Resultantly, it is not possible to situate them physically in any specific *worldspace*.

Dasein is in this world; it presences itself through active interaction and interpretation of other beings. In contrast, all other entities in this world have a physical space. It is thus possible to position them spatially by determining their proximal distance to other beings or *ready-to-hand* objects such as tools (Heidegger 1978). In a sense, through involvement with other beings (both animate and inanimate), *Dasein* give them space or *make room* for them.

Moreover, Heidegger's conception of time diverges from the generally held view of the linear flow of current time. He favors a more revolutionary outlook of time with its "endless, spatialised succession of present moments" (Orr 2014, p. 116) between which beings exist in a state of infinite possibilities. He portrays *Dasein* (human beings) as temporal beings that experience ecstatic time, while all other beings are grounded within a linear progression of time (Orr 2014). Kakkori (2013) notes that "Things in the world have duration, and this duration is given by *Dasein*" (p. 575–576). As a case in point, Kakkori offers the example of a 13-year-old vase. The vase by itself is unable to have time; only *Dasein* have the ability to afford a time duration to it, proving *Dasein's* capacity to constitute and initiate time.

Kakkori (2013) adds that the Heideggerian *ecstases* of time, the present, the past, and the future, do not follow one another but rigorously overlap each other. For instance, references to the past are in reality "the present of the past" (p. 580) because we are situated in the present but reaching out to the past. Similarly, connecting the past to the present makes the present "the future of the past" (p. 581) since viewing the present from the past makes the present the future of the past. Furthermore, Heidegger explains that although the ordinary world view of time enables us to state the time or calculate the time interval between events, it is unsuccessful in capturing the nature of time, "the now moment" (p. 573), because time is constantly advancing toward our future, our becoming. It is only by stretching ourselves *futurally* along the tangent of time and *temporalizing* our being in relation to other beings can the now moment be ontically secured (Johnson 2000; McConnell-Henry et al. 2009; Kakkori 2013). It is evident that existing spatially and temporally is a fundamental dimension of being in the world.

2.6 Verstehen

Hermeneutics is the interpretive understanding of the state of being. Heidegger (1978) posits that *Dasein* exist in a mode of endless possibilities, journeying through life and understanding themselves through the "worldhood of the world" (p. 91), which they inhabit. Beings understand and identify themselves by mediating meaning with other pre-existing entities like nature and other beings. In doing so, interpretation serves to enhance understanding (Wilson 2014). Bonevac (2014, p. 177) suggests that "*Dasein* encounters the world as already structured and already having significance in relation to *Dasein* itself." Heidegger draws on the functions of opening doors or hammering to illuminate the process of interpretive understanding. When implementing practical tasks, beings come across *ready-to-hand* tools, which include doors and hammers. In such situations, they refrain from opening and

shutting the door or weighing the hammer to assess their physical characteristics. Indeed, their prior knowledge enables them to interpret something as something. They project their understanding laterally and associate doors with buildings to work out their purpose (Warnke 2011). Likewise, the purpose of the hammer is determined by relating it with other tools such as nails and boards. The working out of a tool's functionality by looking beyond it and linking it to other entities is an act of interpretative understanding or *verstehen* (Heidegger 1978; Steiner 1978; Risser 1997). Heidegger's philosophy as a whole is disposed toward *verstehen*, the ability of human beings to understand the meaning of life.

2.7 The Hermeneutic Circle

In the hermeneutic enterprise, *verstehen* occurs in a circular movement. As noted earlier, on account of beings existing amidst a matrix of interrelationships, they already possess some knowledge of the world and its entities. The potential to understand meaning lurks in every situation they encounter. By means of collectively understanding other entities and themselves, *verstehen* takes place, implying that in order to understand a part of the experience, one must understand the experience in all its entirety. This apprises us of the circular nature of understanding (Risser 1997). It also thrusts into prominence the fore-structures of understanding in this hermeneutic circle, which play a significant role in meaning attribution: fore-having, fore-sight, and fore-conception. The first fore-structure, fore-having, points to presuppositions about the entity or speculating on what the entity could be. Heidegger draws on his famous example of a hammer to explain this fore-structure. For instance, people who have never seen a hammer would speculate on its use. In doing so, their prior knowledge confers partial meaning onto the hammer by helping them realize that a hammer is a type of tool meant for a specific task. The next fore-structure, fore-sight, increases understanding by helping beings consider more information about the entity to be understood, such as working out that a hammer could be used with nails. Fore-conception completes the hermeneutic circle. It is the process of deriving more complex information about the entity. In the case of the hammer, it is construing that different types of hammers are used for diverse tasks (Heidegger 1978; Risser 1997; Johnson 2000). Overall, the hermeneutic circle involves a back-and-forth movement while making connections between the matrix of interrelations and the entity that is to be understood, in order to arrive at interpretive understanding. To sum up, interpretive understanding is manifested by "refining and piecing together ... local fore-conceptions and fore-understandings into an overall understanding" (Bonevac 2014, p. 179).

2.8 Language: The House of Being

In the hermeneutic circle, language is credited as the channel that communicates understanding. It permits beings to fulfil pragmatic activities like developing and

organizing something, exchanging and debating ideas, and questioning and speculating in order to function effectively in the world (Heidegger 1962, 1978). When engaging in these functional activities, beings become oriented to the world around them through language. Language thus unites the world and enables beings to understand themselves, their world of involvement, and the purpose of life. In short, language energizes our life and activates an understanding of our potential to become. The ability of language to shelter and support beings as they fulfill their everyday tasks has urged Heidegger to refer to it as the house of being (Cammell 2015). In turn, beings dwell in language and draw on it to conclude practical transactions with other entities. Heidegger perceives language not as a coded system, but as an all pervasive being, that bestows on users a shared horizon for communication and understanding to occur (Clark 2011). The foundation of language is discourse, composed of spoken and written text. Heidegger (1978) defines a text as a “a totality of words” (p. 204) that represents the *thereness*, the diverse nature of the world. The key elements of a text are the aim of the text, its content, and the mode of communication. Research on hermeneutic textual discourse illustrates that uncovering the meaning enclosed within a text entails moving past superficial meaning, to an analysis of the relationship between the parts and the whole of the text (Neuman 2006; Ortiz 2009). In brief, language enacts meaning mediation.

The benefits this ontic approach offers researchers, principally, those interested in cross-disciplinary research, are manifold. Before I outline its merits, some of the distinct challenges of disciplinary crossing must be acknowledged. With cross-disciplinary research, I anticipate that the selection of a suitable study design could prove problematic, since it would need to satisfy the requirements of different disciplines. It also calls for interdisciplinary knowledge on the part of the researcher and a broader set of research skills. It is alleged that there are numerous biased attitudes associated with interdisciplinary research (Aagaard-Hansen 2007), with “lack of acceptance of paradigm breaking or shifting” (Karniouchina et al. 2006, p. 274) and an excessively demanding ethics process (Aagaard-Hansen 2007) quoted as prominent obstacles. Besides these obstacles, finding a “publication outlet” for interdisciplinary research findings could be an insurmountable task (Karniouchina et al. 2006, p. 274).

3 Hermeneutics: The Springboard to Cross-Disciplinary Research

The limitations of disciplinary crossing outlined above are duly noted; yet, in higher education, the void and perceived need for interdisciplinary collaboration are acutely felt. In spite of this, literature on cross-disciplinary undertakings is disturbingly thin. What is more, it is worthwhile pointing out that while Heidegger's strand of hermeneutics is applicable to all forms of research, it holds greater promise for cross-disciplinary research. Nonetheless, remarkably, there are no traces of any hermeneutic cross-disciplinary enterprises reported in literature. I make the first

attempt to call attention to this resourceful ontic approach and delineate its profitable alignment with cross-disciplinary research.

With language as the common denominator, interpretive phenomenology could cross over different fields of study and offer researchers a suitable research design that would procure a maximum amount of trustworthy data. As a research paradigm, it would afford a multidimensional view of the lived experience through the lens of ontology (see also ► Chap. 6, “Ontology and Epistemology”). It could bring together hitherto diverse fields such as the sciences and humanities by providing a flexible, interpretive framework that would broaden the scope of enquiry and generate new insights. What follows is an account of the hybrid benefits hermeneutics bestows on cross-disciplinary researchers.

3.1 Addressing Complex Phenomena

Employing hermeneutics allows cross-disciplinary researchers to get immersed in complex phenomena. It assists in unearthing different layers of meaning as the phenomena are examined from different perspectives. For instance, as a cross-disciplinary researcher, I undertook a research project on *Genre Mixing in Undergraduate Nursing Texts*. Using hermeneutics as the philosophy and analytical approach, the study dwelt on the research question: *What does it mean to be a student nurse?* This entailed a focus on the identity of student nurses, their goals, and their existence in the world of *sorge* (care), that is, the manner in which student nurses are prepared to care for their patients; the relationships they form with other student nurses, tutors, literacy staff, and clinical facilitators; and the influence of these relationships on students’ academic progress. Crossing the boundary from nursing to education also allowed me to conduct a language study into the becoming of the beings who deliver care (student nurses). It enabled me to research their assignment writing practices at university and the triggers and barriers to students’ writing competency. Using hermeneutics as the analytic tool strengthened the cross-disciplinary endeavor for it provided the means of seeing the phenomena in its entirety and brought to light the way student beings exist spatially and temporally in the world of nursing by *making room* for the other entities they encounter such as work, family, friends, and assessment demands. Moreover, I drew on the hermeneutic circle which is best suited to addressing complex phenomena. The hermeneutic circle provides interdisciplinary researchers a platform to lay bare the research question and examine the fore-structures of understanding, by relating the parts of the phenomenon to the whole of the research experience. Hermeneutic questions that might guide researchers in this process are: *Would the aspects of the phenomena being studied contribute to answering the research question? Are there any aspects of the lived experience that might prove elusive? Have I planned for variability in the study?*

In the study on *Genre Mixing in Undergraduate Nursing Texts*, the hermeneutic circle permitted a close scrutiny of the interview data, to piece together the parts and whole of the text to generate a comprehensive picture of the phenomena in all its dimensions. It traced the *being and becoming* of student nurses as they access the

range of possible support resources at their disposal, learn to overcome their writing deficiencies, write precise nursing documents, and communicate information clearly. It authorized me to study not only human behavior and the web of interrelations between people but also the language that defines human interactions, thus coinciding with the disciplines of health and social sciences. From the evidence outlined, it is possible to infer that hermeneutic cross-disciplinary interests empower researchers by stretching their range of vision and facilitating innovative solutions to the problematic under scrutiny.

3.2 Adding Depth and Breadth

In contrast to mono-disciplinary studies, a multidisciplinary endeavor founded on a hermeneutic base adds depth and breadth to the research undertaking. While hermeneutic studies in a single discipline have proved fruitful, they lack the unique richness of interdisciplinary research. The latter serves as a bridge between disciplines, fosters new ways of thinking, and extends the foci of the study over a broader area. Cross-disciplinary researchers consider the relevance of the study to their own discipline and verify data gathered by analyzing it from a cross-disciplinary perspective. This is done by actively exploring the lived experience through several modalities and in all its different aspects. Doing so negates bias and provides a fuller, richer description of the lived experience. Furthermore, positioning cross-disciplinary research within hermeneutics also shifts it from a passive, positivist form of cognitive understanding to an active, dynamic form of interpretive understanding (see also ► [Chaps. 9, “Positivism and Realism,”](#) and ► [“Social Constructionism”](#)). In brief, cross-disciplinary hermeneutic studies broaden practical and scientific outcomes, make a valuable contribution to new knowledge, and attract wider exposure to multidisciplinary issues.

3.3 Providing a Selection of Interpretive Methods

Heideggerian hermeneutics helps cross-disciplinary researchers exploit the most appropriate modes of enquiry. Interpretivists use interviews, texts, and participant observation as data-gathering methods. Drawing on these methods and ensuring that they coincide conceptually with the philosophy of the study grant cross-disciplinary researchers the leverage to obtain richer and more in-depth information about the whole experience. Of the interpretive methods listed, textual analysis is frequently used because it permits researchers to listen to the speech of language in its written form. This happens when researchers listen to the story that is narrated in the text by participants of the world (see also ► [Chaps. 47, “Content Analysis: Using Critical Realism to Extend Its Utility,”](#) ► 48, [“Thematic Analysis,”](#) ► 49, [“Narrative Analysis,”](#) and ► 28, [“Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”](#)). In an interdisciplinary enterprise, the speech of the text could be more pronounced because things in the world speak to researchers from different perspectives and from diverse roles.

For example, an educational researcher could conduct a textual analysis on health science students' writing to understand the writing practices in health science. In this context, the disciplinary boundaries of education and health science are bridged in order to fully explore the phenomenon through diverse modalities. The data in the text could speak to the researcher in hybrid ways and unveil the writing requirements of health science students, their attitude to their discipline, and their roles and aspirations as students. All this information is revealed through the speech of the text. On the other hand, a mono-disciplinary study would only provide a flattened view of the world.

It is worth noting that multimodal, cross-disciplinary analysis calls for the researcher to be more attuned to the nuances of meaning in the text, attitudes expressed, and world views that emerge. A distinct requirement for quality textual analysis is listening to the silence of the text. Silence here refers to opinions, beliefs, attitudes, or cultural practices that are not conveyed but lie implicit in the text. It is also possible to combine heterogeneous methods such as interviews and textual analysis or interviews and participant observation in order to enrich research outcomes. Therefore, employing hermeneutic methods and conducting studies of such magnitude endow a phenomenological seeing to cross-disciplinary researchers.

4 Conclusion and Future Directions

The rapidly changing knowledge society demands novel ways of thinking and being that contribute to original research. Added to this, with technological advancement and increased complexity of issues, the need for research that opens up rich avenues of multidimensional enquiry is recognized. Most importantly, the paucity of such research in health and social sciences is increasingly noted. The multiplicity of health issues experienced by patients and their families and the academic challenges encountered by students and academics in higher education contexts warrant an exclusive approach to data gathering and analysis. Hermeneutic studies that cross disciplinary boundaries and delve into the fullness of the lived experience emerge as an asset that could power such research ventures.

A cross-disciplinary hermeneutic endeavor in tertiary education is a new concept. It is a legitimate mode of enquiry that would invigorate research practices and provide the means for researchers to capitalize on the potentiality of different disciplines and corroborate findings from an interdisciplinary perspective, through the multifocal lens of hermeneutics. However, it must be acknowledged that hermeneutic disciplinary crossing is a time-consuming and laborious process. It requires researchers to expend time understanding the core concepts of hermeneutics to avert the risk of misconstruing them and conceptually and methodologically misaligning them with their research project. Admittedly, these aspects ought to be considered when planning a hermeneutic cross-disciplinary investigation; but the benefits far outweigh any possible disadvantages in terms of time and effort.

It is envisaged that this chapter would generate sufficient interest in hermeneutics and set the trend for the convergence of hermeneutics and interdisciplinary research.

Interest in dynamic research paradigms such as hermeneutics should be fostered in undergraduate studies and nurtured right through to postgraduate research degrees. For instance, most undergraduate degrees in health and social sciences have an introductory research-based unit to orient students to the purpose and basic principles of research; help them make sense of conceptual frameworks, data collection, and analytic methods; and practically apply their research knowledge to drafting a brief research proposal. Strongly embedding hermeneutics into undergraduate coursework and continuing to scaffold it into postgraduate studies would make it more approachable as a research paradigm. Flowing on from undergraduate degrees, postgraduate research degrees too need to offer hermeneutics as an intrinsic part of the course curricula, with aspects of hermeneutics modelled by experienced researchers through workshops and hands-on interpretive analysis of data. These strategies would demystify the world of hermeneutics and make it more visible for new researchers and doctoral students grappling with methodological concerns. Allocating grants for cross-disciplinary research in higher education would also encourage more cross-disciplinary collaborations and motivate researchers to turn to multifaceted research paradigms and methods of enquiry such as hermeneutics to enhance trustworthiness and enrich research outcomes. I hope that this chapter will give fellow researchers the impetus to cross disciplinary boundaries and move from *being to becoming*, from the actuality to the possibility of their *being*!

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Feminism and Healthcare: Toward a Feminist Pragmatist Model of Healthcare Provision

12

Claudia Gillberg and Geoffrey Jones

Contents

1	Feminism and Healthcare: Starting Points	206
2	Politically, Historically, and Culturally Embedded Healthcare	207
3	Paternalism Within Healthcare	208
4	Healthcare for Whom, How, and Why?	210
5	Why Paternalism Is Not Necessarily Remedied with Concepts and Practices of Gender Equality	211
6	Empirical Examples of Ontological and Epistemological Absences	212
6.1	Sick and Disabled Women's and Men's Experiences of Receiving Healthcare	212
6.2	Hysterical Women	213
7	Paradigmatic and Ontological Struggles Within the Medical Profession and Other Healthcare Personnel and Its Implications for Patients	215
8	A Problem-Solving Paradigm: Feminist Pragmatism	216
9	Solutions	216
10	A Feminist Pragmatist Discussion	217
	References	219

Abstract

This chapter covers a range of topics pertaining to the ontological, epistemological, and ethical intricacies, complications, and possibilities of providing quality healthcare to women patients regardless of disability, race, ethnicity, and class by using empirical examples of certain diseases. Methodological concepts through reflections on subjectivity and objectivity are presented as contested issues, and radical objectivity, a concept comprising subjectivity, objectivity, and

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intersubjectivity, is proposed as a knowledge paradigm that allows healthcare personnel and patients to make knowledge claims that are mutually recognized as valid. Three models of healthcare, paternalistic, person-centered, and feminist pragmatist, are presented, outlining the specific problems inherent in each model of healthcare provision. The paternalistic model allows for no agency on the patients' part, elevating healthcare personnel, specifically doctors, to authoritative knowers. The person-centered model of healthcare grants some shared responsibility between healthcare personnel and patients, and some concessions are made toward patients as knowers. In the feminist pragmatist model, healthcare personnel and patients commit to equal relationships. Gender equality and gender equity are identified as insufficient tools for organizational change, and theories of professions are drawn on to deliberate about change at the systemic level.

Keywords

Feminism · Methodology · Ontology · Epistemology · Paternalism · Pragmatism

1 Feminism and Healthcare: Starting Points

Feminism and healthcare is a topic so complex that no one could ever hope to cover it satisfactorily in a single chapter. Choices regarding perspective, suggestions, selection of examples of problems, and solution-oriented proposals must be made. These are the author's choices, an author who is herself disabled by chronic disease, and is an academic. My views are colored due to my experiences of healthcare and the body I live in and with which I encounter the outside world. My ontological and epistemological points of departure are (a) women are human beings and entitled to fully participate in society, (b) "women" is not a generic term but consists of variations of being a woman and the perception by others of "woman's" multiple meanings, and (c) a belief in collaborative knowledge building.

This revelation will be understood by some as biased, subjective, and therefore invalid. Based on their understanding of valid knowledge and scientific rigor, there are ontologies and epistemologies that stand in stark contrast to the research and knowledge paradigm within which I operate (Herr and Anderson 2005). In my paradigm, feminist pragmatism, it is encouraged to reveal points of departure for critical appraisal by others and then use new/other perspectives as an enriching and fundamentally necessary contribution toward a more comprehensive understanding of healthcare. It is argued that in doing so, other forms of knowledge will be elevated with the power to reject other forms, but in this chapter I envisage the reader as unfamiliar with this line of reasoning and as malleable toward accounting for what others perceive as unscientific, anecdotal, or invalid (Minnich 2005).

It is this uniqueness of each "knower's" perspective and experience (here of healthcare) that is welcomed by feminist pragmatists exactly because multifarious perspectives, when listened to and used toward problem-solving, have the potential to and often do contribute to areas in society that are better equipped to offer solutions, benefiting more people than the few belonging to an elite whose views

traditionally infuse policies, practices, and entire societal systems (Minnich 2005; Gillberg 2012). To understand this chapter is to acknowledge the existence of other paradigms than the alleged objectivity and neutrality offered in so many research disciplines, that, on closer inspection, rarely offer objectivity in terms of justice being done to all in equal measure, as research questions remain only partially or underinformed and results will not always enable a broad application of newly produced knowledge (Andrist 1997; Anjum 2016; Gillberg and Vo 2014; Minnich 2005; Reid and Gillberg 2014). Feminist pragmatists will ask questions such as for whom is knowledge produced and where “best practice” is devised. For this chapter, I have drawn on several aspects of healthcare, geographical diversity, and texts that span decades to convey some continuity for this complex and difficult topic.

2 Politically, Historically, and Culturally Embedded Healthcare

Healthcare is historically embedded in political systems and cultures with ongoing power struggles and shifting game plans coupled with ideas about privatized or public healthcare, healthcare rationing, and other rationales that have little or nothing to do with human beings’ needs (Kennedy 2012; Lian 2017; Nott 2002; Sherwin 1992). Such factors perpetuate inequalities prevalent in healthcare while they also create new problems. Some inequalities can be summed up as inadequate or no access to primary healthcare, long waiting times to receive an appointment for specialist care depending on where in a country or in which country patients live, and gendered notions of patients on the part of healthcare personnel (Cody 2003; Cook et al. 2017; Evans and Mafubelu 2009; Risberg et al. 2009).

Occasionally, as occurred with AIDS and women, battles are won, though not without personal tragedies and loss of life (Epstein 1996; Shotwell 2016). Health policies, official guidelines and diagnostic criteria, curricula for medical students, access to primary and specialist healthcare, health insurance policies, funding of research and inadequate to no treatments for certain conditions can, and often do, have dire consequences for people’s lives (WHO 2015; McDonnell et al. 2009).

While ontological and epistemological approaches in inquiry are culturally, ideologically, and politically informed, other factors contribute to healthcare remaining lacking for many women and men, but at the macrolevel inequalities in healthcare affect women more than men rendering chapters such as this a necessity. Differing schools of thought in medicine and organizational theories can constitute colliding ideas about how to organize healthcare in relation to notions of who, and what, the patient is. Patients can be many things to healthcare providers, which relates to academic disciplines’ predominant narratives about patients but also with what constitutes a disease. It could be argued that these other factors, to a large degree, belong to the field of theories and studies of the professions and issues pertaining to power and the struggle for recognition of expertise (Freidson 1993). Such a struggle occurs both within a profession and between different professions within the same organization or system. Healthcare

represents the fulcrum of such a struggle. It is also a struggle in the field of tension between professions and organizations (Andrist 1997; Butler et al. 2004; Fenton 2016a, Fenton b, Freidson 1993; Hafferty and Light 1995; Hsu 2010; Humphries et al. 2017; Klein 2004; Light 2000; Pescosolido 2013; Risberg et al. 2009; Steen 2016; Tasca et al. 2012).

3 Paternalism Within Healthcare

There are schools of thought that dismiss patients as knowers altogether, ridiculing entire patient populations, especially women patients (Fenton 2016a; Kennedy 2012; Lian and Robson 2017; cf. McEvedy and Beard 1970; Mickle 2017; Mitchell and Schlesinger 2005; Robson and Lian 2017; Staples 2017). The paternalistic school of thought deserves special mention, because it is in this paradigm that women have historically fared the worst (Fricker and Hornsby 2000; Sherwin 1992; Webster 1996, 2003; Wendell 1996). Cody (2003, p. 288) provides a definition of paternalism as:

Paternalistic practices, wherein providers confer a treatment or service upon a person or persons without their consent, ostensibly by reason of their limited autonomy or diminished capacity, are widespread in health care and in societies around the world. . . . Numerous issues surround paternalistic practices.

Cause for alarm arises due to a branching off in recent decades to extreme paternalistic schools of thought, which evidence suggests is thriving, raising the question as to why such an ontology, because it is first and foremost an ontology in my opinion, has a place in healthcare systems.

Ideally the aim should be for a relationship between the patient and medical personnel as defined by Govender and Penn-Kekana (2007, p. 4),

A good interpersonal relationship between a patient and provider - as characterised by mutual respect, openness and a balance in their respective roles in decision-making – is an important marker of quality of care.

I would propose and argue that there are three models of healthcare provision regarding “what is” and “whose/what knowledge counts,” only one of which meets the above specification, and these are:

1. The Paternalistic Model

View of patient: The patient has no agency as a lay person and is therefore ignorant.

View of knowledge and learning: Only the medical doctor knows. Patients may be able to learn from their doctors but must recognize the latter are superior. Learning is one-dimensional and one-directional. Knowledge is objective and static.

View of medicine: What is, is, whatever the medical profession determines as true and valid. There are no margins for uncertainty on the part of the doctor.

View of impact of treatment and outcome validity: It is the patient's responsibility to comply with prescribed treatments. If the outcome is undesirable, punitive measures for the patient will ensue; since the patient has no agency, only the medical doctor's knowledge has validity.

Outcome: Recovery is determined by the medical personnel irrespective of the patient's opinion, related to continued ill-health. Patients are discouraged from seeking further help.

2. **The Neutral Patient Model**

View of patient: The patient is neutral and ascribed value as a situated, subjective knower. As such, the patient possibly holds information that will be of use to medical and other healthcare personnel.

View of knowledge and learning: Knowledge is not one-dimensional since the patient is granted agency and recognized as knowing to some extent.

View of medicine: Medicine is a fluid field of knowledge, and learning is ongoing. What is best for the patient is a semi-open question, but ultimately healthcare personnel know better, and their advice ought to be followed.

View of impact of treatment and outcome validity: Patients as subjective knowers are entitled to report back and be believed if a treatment does not yield the desired outcome. Healthcare personnel will reconsider and discuss new ways forward with the patient. Outcome validity is determined by both medical doctors and patients.

Outcome: Partially shared responsibility for improved health, if symptoms persist and patient continues seeking medical help, uncertainty ensues. The patient is likely to be treated in a paternalistic manner due to system structure.

3. **The Feminist Pragmatist Model**

View of patient: The patient is a nonconforming, knowing human being in her own right, embodying a plethora of experience and perspective that may prove useful in solving the problem at hand; in other words, patients have full agency and are regarded as equals.

View of knowledge and learning: Knowledge is best constructed from a multitude of perspectives and must have a clearly defined applicable purpose to open-mindedly address problems with a view to satisfactorily resolving them in collaboration with those affected by the problem. Learning is a process, ideally grounded in meticulously researched fact and lived experience.

View of treatment and outcome validity: A genuine interest in the patients' account of improvement or recovery. A treatment is only valid if the patient says the situation has been resolved satisfactorily.

Outcome: Based on system structure, it is unclear how far this model can accommodate patients with long-term healthcare needs. Theoretically, recovery occurs only if the patient says so and resumes pre-illness activity levels, which is acknowledged by the medical personnel.

These models are not discrete; there can be movement between models, barring the extreme paternalistic form, which arguably functions as a rigid ideology. While models are never complete or an accurate reflection of real-life situations, those detailed above might prove helpful in outlining the possibilities and obstacles

healthcare personnel and patients can face. It is not easy to question one's paradigmatic base let alone to arrive at the decision that an absolutist stance in healthcare does not and cannot translate into solidarity with patients when educated in model 1, especially if one's belief in medical knowledge's absolute expertise stands firm. However, it might be possible for those located in model 1 to acknowledge that patients are complex and knowing participants in society unlike the empty vessels that a strict positivist paradigm traditionally suggests. Even the most extreme paternalistic medical practitioners today should be able to recognize that patients are a heterogenic group of people with varying backgrounds, knowledge, and scientific and medical expertise. The fact that members of the healthcare professions and scientific communities fall ill, and that they are capable of critically appraising and discussing guidelines and policies, and offers of help by assessing research designs, selection criteria, methods, outcomes, research validity, and have insider knowledge of peer review processes, and that some of these patients will engage in informal learning settings to share and disseminate their knowledge rarely register with the paternalistic groups of medical practitioners. Once a patient, regardless of educational background and professional base, the reconstruction into an infantilized unknowledgeable subject without agency categorically occurs. A dismissal of capacity and ability on the part of patients holds no value, nor do measures that do not work qualify as serious offers of medical support.

Particularly at risk for paternalistic or extreme paternalistic encounters are patients with diseases whose symptoms are either designated as vague and diffuse or whose etiology is unclear (Lian 2017; Sherwin 1992; Wendell 1996). The illogical attribution of what counts as a serious illness, e.g., multiple sclerosis (MS), versus what is considered by some as an insignificant non-illness, myalgic encephalomyelitis (ME), despite extensive symptom overlap is a decision that leaves patients, many of them women and children, living precarious lives. In marketized, neoliberal academia, research that promises allegedly cost-effective results is produced that policymakers adopt and politicians propagate.

4 Healthcare for Whom, How, and Why?

Since this is a handbook about methods in healthcare, the risk of conflating method with methodology requires highlighting. For those unfamiliar with the distinction between method and methodology, methodological issues touch upon questions of ontology, epistemology, and ethics. In its shortest form, key ontological, epistemological, and ethical questions are:

1. What is? (ontological)
2. Knowledge for whom and why? (overlapping ontological and epistemological question)
3. What counts for knowledge/whose knowledge? (feminist epistemological interlinked questions)

4. What are the consequences of 1, 2, and 3? (reflection)
5. Does the privileged/more powerful party take responsibility? (feminist ethics)

These questions are fundamental as they produce answers that transcend the current rationale for healthcare provision, indicating the type of society healthcare personnel assume they are part of and contribute to, which is particularly important.

Methodology is more than deciding on methods for inquiry. Feminism, and specifically pragmatist feminism, encompasses a problem-focused questioning of healthcare provision as there is no such thing as an unbiased researcher, clinician, or healthcare practitioner, neutral in their approach to inquiry and clinical practice. Medical research is colored by the investigator's preconceived notions and their interests (Edwards 2017; Geraghty 2016; Goldin 2016; Racaniello 2016; Staples 2017). Even rigorous and scientifically robust studies can yield results that are problematic, especially in the field of tension between the natural and social sciences, where doing science is not mathematically clear-cut and the parameters of what we need and ought to know are blurred. Many research questions that ought to have been asked and to have received funding have gone unasked, and been unfunded, leaving knowledge gaps detrimental to patient groups neglected due to their diseases lacking medical prestige (Bosely et al. 2015; Brown 2017; McEvedy and Beard 1970; Payton 2016; Risberg et al. 2009; Staples 2017; Wu et al. 2016). Consequently, there are many issues pertaining to women's health and well-being that healthcare providers are ignorant of, be that willful ignorance owing to aforementioned rationales, belonging to schools of thought that dismiss entire patient groups, or actual ignorance in terms of not knowing. This is not a new or obscure phenomenon, as the research literature indicates (Andrist 1997; Kennedy 2012; Sherwin 1992).

A tenet of feminist inquiry is the acknowledgment that the most open-minded researchers are ontologically challenged (regarding the "what is?" and therefore, also, regarding the "what is not?") as they are embedded in their cultures, academic disciplines that frame valid and to them relevant research in certain ways, and the political systems responsible for the organization of healthcare. Health policy, too, is infused with cultural notions about society's order, e.g., women's reproductive role, motherhood and women in the public sphere, and women as primary caregivers. Certain diseases are recognized in some countries but not in others or are culturally ascribed to a specific sex. To recognize that healthcare in any country is a political and cultural undertaking, influenced by notions of gender, social class, race, ethnicity, and chronic illness, and what constitutes a disability, is a vital first step toward an understanding of the place of feminism and as a logical extension, feminist-driven inquiry, in healthcare.

5 Why Paternalism Is Not Necessarily Remedied with Concepts and Practices of Gender Equality

Feminism in healthcare is partially about gender bias, but gender per se is not synonymous with feminism. To outline terms and definitions, a brief overview of terminology may be helpful (Risberg et al. 2009).

While the concepts of sameness/difference are inherent to theory, it is less clear how to define, interpret, and apply these concepts:

- A. On an ontological level, issues of sameness/difference pertain to essentialism; in other words, are women and men the same or are they different, and if they are the same/different, how so? Practically speaking, this means whether or not women have the same rights as men and have or should have access to all sections of society. A relevant question in this chapter would be if we think that women should become surgeons, and if we think that, why we think this is a good idea. Is it, for instance, because they are human beings just as men are, with individual and divergent skills and interests, or because they represent other values than men and therefore have something to add?
- B. On the epistemological level, discussions are about whether sameness/difference provides researchers with solid tools to ask meaningful research questions. Problems of difference/sameness are rooted in essentialism. The norm, as many claim, is still male, both in theory and clinical practice, so “sameness” can easily be mistaken “same as men”; in other words, women and men are the same provided that women behave like men and adjust to male norms. This would explain why there are women within paternalistic healthcare systems who suppress and mistreat women patients just like their paternalistic male colleagues. It is the system that is paternalistic per se. Recruiting more women into such a system does not make the system better for women patients; it remains the same, with the women adopting male norms in order to succeed. This also explains why gender awareness or even challenging gender bias does not necessarily entail fairness or inclusion, far from it.

6 Empirical Examples of Ontological and Epistemological Absences

6.1 Sick and Disabled Women’s and Men’s Experiences of Receiving Healthcare

In a recent study (Lian and Robson 2017), patients in Norway described the power struggle with healthcare personnel and medical doctors in terms of war metaphors. As previous studies indicate, physical symptoms inexplicable by current biomedical testing are a particularly contentious area characterized by conflict between patients and medical personnel (Bosely et al. 2015; Brown 2017; Edwards 2017; Geraghty 2016; Goldin 2016; McEvedy and Beard 1970; Racaniello 2016; Staples 2017):

We found that patients experience being met with disbelief, inappropriate psychological explanations, marginalisation of experiences, disrespectful treatment, lack of physical examination and damaging health advice. The main source of their discontent is not the lack of biomedical knowledge, but doctors who fail to communicate acknowledgment of patients’ experiences, knowledge and autonomy. War metaphors are emblematic of how participants describe their medical encounters. The overarching storyline depicts experiences of being caught in a power

struggle with doctors and health systems, fused by a lack of common conceptual ground. (Lian and Robson 2017)

How can such inequities and inequalities be understood?

6.2 Hysterical Women

We should look upon the female state as being as it were a deformity, though one which occurs in the ordinary course of nature. (Aristotle, in Fricker and Hornsby 2000, p. 13).

The concept of hysteria dates to ancient Egypt though the term was used originally by Hippocrates who blamed the “disease” on uterus movement due to a lack of sexual activity in women (Tasca et al. 2012). Freud promoted the psychological model of hysteria, including men as potential sufferers, though the diagnosis is more commonly attributed to women. A more recent example is provided by ME, classified by the World Health Organization (WHO) as a neurological condition since 1969 following an outbreak at the Royal Free Hospital in 1955 (Tasca et al. 2012). In January 1970, two male psychiatrists, Colin McEvedy and William Beard, published a paper in the *British Medical Journal* that claimed, without either researcher examining any patients, that the Royal Free outbreak was a case of mass hysteria due to more women being affected: “Epidemic hysteria is a much more likely explanation. . . The data which support this hypothesis are the high attack rate in females compared with males.” That such conjecture can be classed as data, even in 1970, is a question that directly ties into methodology and the choices doctors make to this day, thereby perpetuating discriminatory practices in healthcare (McEvedy and Beard 1970; Staples 2017; Tasca et al. 2012). It is unfortunate that such blatantly sexist, untestable opinions can be so influential on the medical profession. The paradigmatic struggle continues, with the paternalistic school of thought (demonstrated via psychogenic models with little scientific basis), practiced by both male and female medical personnel, which originated with McEvedy and Beard’s work, still influencing the treatment of ME patients and sufferers of other conditions (Steen 2016).

Ascribing symptoms of organic illness in women as psychologically based “hysteria” has a long history; Freud diagnosed a 14-year-old girl as suffering with an “unmistakable hysteria,” claiming she was cured following his treatment. In fact, she continued to complain of abdominal pain and died within months of sarcoma of the abdominal glands (Webster 2003).

Arguably, use of the term hysteria has led doctors to believe they have found a diagnosis for symptoms, which in fact remain unknown, meaning they may miss organic medical conditions (Webster 1996). The psychiatrist Eliot Slater conducted a study of 85 patients diagnosed with hysteria in the 1950s. Upon follow-up a few years later, nearly half these patients had died or were suffering from a significant disability. One patient, a woman suffering from severe headaches, was diagnosed with “conversion hysteria” and within 2 years had died from a brain tumor (Webster 1996). Misdiagnosis of both men and women by the medical profession is hardly

unknown, but the readiness of medical practitioners to ascribe a woman's symptoms as psychological (read "hysterical") in origin is problematic and can result in serious consequences (Steen 2016).

Webster's quote is especially relevant given the rise of medically unexplained symptoms (MUS) where the paternalistic school proposes patients presenting with new symptoms be ignored and encouraged to undergo corrective or rehabilitative cognitive behavioral therapy (CBT) and similar "treatments" that often provide limited or no benefit to patients (Butler et al. 2004; Fenton 2016a; Kennedy 2012; Steen 2016; Tasca et al. 2012). The medical ethos, transmitted through medical training, introduces an inherent bias in how medical professionals approach the treatment of women compared to men, encouraging the dismissal of women's concerns regarding their health and often treating female patients in a condescending fashion (Fenton 2016a; Freidson 1993; Mickle 2017; Sherwin 1992).

The paternalistic paradigm is particularly evident when applied to women presenting physical symptoms to a doctor. Medical personnel are more likely to ascribe a woman's symptoms as emotional rather than organic in origin, resulting in misdiagnosis or the potential ignorance of serious medical conditions (Steen 2016) and poor treatment options and abuse – the patient led to believe they are responsible for their symptoms (Fenton 2016a; Mickle 2017).

For example, women are 50% more likely to be misdiagnosed following a cardiac arrest compared with men (Wu et al. 2016), which has a major impact on future health, reducing quality of life as un- or incorrectly treated heart attacks can result in irreversible damage to the organ - nearly 28,000 women die from cardiac arrest annually in the UK (Payton 2016). Women are also 30% more likely to be misdiagnosed following a stroke, and there are often significant delays in diagnosing serious conditions including autoimmune diseases, e.g., MS, which take an average of 5 years to be diagnosed, and endometriosis, which can take up to a decade (Mickle 2017).

A stark demonstration of gender variation in medical care is demonstrated through the treatment of pain (Fenton 2016; Hofman and Tarzian 2001). Women's pain is more likely to be dismissed, and female patients are less likely to be given adequate pain medication than men. In UK Accident and Emergency departments, women and men presenting with similar abdominal pain receive different treatments, men waiting an average of 49 minutes for treatment compared to 65 minutes for women; the latter also receive lower levels of pain medication independent of body mass factors (Fenton 2016; Hoffman and Tarzian 2001).

Clinical studies determined that medical personnel consider female pain more likely to be emotional in origin, their pain "all in the mind." This is alarming given evidence that doctors maintain such opinions even when clinical testing indicates the pain is real (Fenton 2016). Thus, pain in women is given a lower value than pain in men. Women experiencing chronic pain have an increased likelihood of being diagnosed with a mental health condition and prescribed psychotropic drugs (Calderone 1990; Fenton 2016; Hoffman and Tarzian 2001). This is harmful for both the mental and physical health of the patient, treating the condition as psychological may lead to serious organic conditions being undiagnosed and untreated.

Historically the ignoring of period pain, which can be as severe as that experienced during a heart attack, provides an example of the lower value placed on pain in women, “Despite affecting women and trans men around the world for days every month, the pain involved in menstruation is seldom questioned nor are serious attempts to alleviate it mentioned” (Fenton 2016).

The condition endometriosis affects 10% of women of reproductive age (approximately 176 million women globally) but, despite its debilitating effects, is often ignored or dismissed by the medical profession (Bosely et al. 2015). This situation has arisen due to the failure of the profession to investigate a “woman’s issue,” resulting in millions of women having their quality of life severely limited. Many GPs and specialists are ignorant of the condition leaving women to suffer for years without treatment. The UK has approximately 1.6 million sufferers, and the cost to the economy is estimated at £10.6 billion, yet research funding is limited, and women are often told to endure any pain or informed it is imaginary, “it’s in your head, girl. You have got to deal with it” (Bosely et al. 2015; Butler et al. 2004; Kennedy 2012; Nott and Morris 2002).

7 **Paradigmatic and Ontological Struggles Within the Medical Profession and Other Healthcare Personnel and Its Implications for Patients**

Much has been said concerning hierarchies within the medical profession and the paradigmatic delineation between medical specialties as well as the relationships within the different healthcare professions (Epstein 1996; Freidson 1993; Hafferty and Light 1995; Klein 2004; Lian and Robson 2017; Light 2000). These relationships create areas of tension and power struggles within the profession, leaving patients awkwardly posited. There are problems within the healthcare professions regarding status, prestige, conceptual framing of diseases, as well as fundamental differences in how patients are approached by members of different professional groups. This must be considered when discussing changes or the possibilities of ontological shifts in health and healthcare, particularly for the following reason: points of departure are so differently evolved that some healthcare personnel are far from an ontological shift toward, for instance, person-centered healthcare ((PCH) (Anjum 2016)). At one end of the scale are paternalistic or extreme paternalistic groups, the latter opposing patient participation unless to tick boxes if a funding body requires it, while others operate within a person-centered paradigm to varying degrees and with some success, e.g., medical action researchers who actively seek to involve patients because of a genuine desire for the patient. Impact of inquiry remains unclear, as discussed in a recent study (Cook et al. 2017). Methodological issues regarding long-term effects, recovery, accountability, and genuine participation on the part of the patients require further research and possibly better frameworks for (participatory) evaluation.

In addition, the medical profession has arguably undergone a de-professionalization in recent decades owing to new public management and state-imposed limits on

the profession (Bezes et al. 2012). Medical doctors' scope for action has to some extent been curtailed by new public management (NPM) (Bezes et al. 2012), but this is not the only reason for the uncertainties with which the medical professions grapple, and there are several discernible ontological movements in opposing directions, further complicating an understanding of possible ontological and epistemological changes in healthcare. The *ethical* consequences of a combination of a weakened medical profession, less time for patients and research due to more time spent on administration, and neoliberal ideology, people are responsible for their own health, as well as neoconservative forces, conjecture of the deserving versus undeserving, proactively aided and upheld by some medical schools of thought, are disadvantageous for patients presenting with "diffuse" symptoms within societies where the mainstream media no longer investigates ideological claims made by governments but instead propagates images of malingerers and benefits scroungers despite sound research clearly indicating that fraudulent behavior is minimal and an ideologically upheld myth (Duffy 2013; Stewart 2017).

8 A Problem-Solving Paradigm: Feminist Pragmatism

As for the possibilities of a transformative change toward a feminist pragmatist paradigm, ontological and epistemological trends occur on several levels, for one on the scientific level where scientific evidence is produced that debunks other findings as fatally flawed (Gillberg 2012; Minnich 2005; Reid and Gillberg 2014). Currently we see such a scientific struggle unfold between the upholders and defenders of trials that have been revealed as containing serious fallacies and flaws (Edwards 2017; Geraghty 2016; Goldin 2016; Kennedy 2012; Minnich 2005; Nott and Morris 2002; Racaniello 2016; Sherwin 1992).

At the grassroots level, ontological shifts are attempted by knowledgeable patient advocates moving in paradigms different to paternalistic hegemonies or entirely outside them. Concerning acquired immunodeficiency syndrome (AIDS), women advocates and women-specific symptoms and suffering led to revolutionary ontological, epistemological, and ethical shifts (Epstein 1996; Shotwell 2016).

9 Solutions

A solution-focused epistemology in combination with a person-centered ontology seems a sensible proposition. A feminist pragmatic approach would allow the healthcare professional to feel recognized and respected while providing room for patients to express themselves. The focus is placed on the problem that requires solving rather than on the patients' class, disability, or sex. It allows clinicians and patients to disregard ongoing power struggles between paradigms, at least to some extent, creating room for change. Furthermore, a solution-focused approach encourages medical practitioners to unpack their medical knowledge and apply their scientific curiosity.

Humility toward what we ought to know might not be known yet and humility toward another human being seeking help for the discomfort they are in, a fundamental belief in human dignity, are essential to the practice of medicine and provision of healthcare. In other words, while we cannot know what we don't know, the choice to listen to patients without prejudice *can* be made. A concession regarding the patient's knowledge about their specific reason for seeking help *can* be made.

There are further choices for healthcare personnel that could be described as feminist and can become pragmatist in addition, by concentrating on the impact they have and resulting feedback (what works/does not work), allowing for evaluation, critical debate, and renewed and improved efforts to enhance healthcare. But is PCH enough provided there is a genuine ambition to end inequalities due to sex, color, race, social background, and disability? PCH is a significant step in the right direction but may not have the capacity to bridge the gap between healthcare providers and women-specific problems concerning accessing and receiving adequate treatment (Nott 2002). For one, "person" is not a powerful enough word or concept to capture the complexities of being a woman seeking medical help, as the empirical examples above illustrate. The noun person suggests an imagined homogenous patient who responds well to drug treatments designed for a perceived average patient. While this has advantages, gender stereotyping is already built into "person." Healthcare personnel are only human and will continue to ascribe characteristics and symptoms to a sex.

PCH heralds a shift in ontological and epistemological repositioning, away from paternalistic paradigms, as it becomes impossible to apply methods which are in stark contrast to ontologies such as evidence-based medicine, as the latter effectively disregards individuals' suffering. PCH presents a viable alternative to a paternalistic healthcare model as the former requires genuine consideration of an individual's health, something that cannot be easily accommodated within a methodology that "ultimately reduces uniqueness and complexity to the sum of various averages, or derives individual propensities from statistical frequencies" (Anjum 2016).

10 A Feminist Pragmatist Discussion

A step further, then, the feminist pragmatist proposition, simple as it may seem initially, is subversive in that it enables medical professionals to reassert their expertise instead of acting as the state's extended arm in stripping patients of their right to adequate healthcare (Stewart 2017). Medical doctors who put patients' health problems first until they are satisfactorily resolved would commit an act of medical empowerment as well as empowering their patients, rejecting dogmatic administrative dictates of whichever economic rationale they must operate and negotiate their professional expertise under (cf. Freidson 1993; Pescosolido 2013; Risberg et al. 2009). This is a pragmatist stance that becomes feminist the moment medical practitioners recognize and acknowledge that women-specific healthcare is a prerequisite to resolve problems that indeed are women specific. Heterogeneity,

“otherness,” and embodied experience of health would become the norm in encountering “woman,” be that a cis woman, an old woman, or a young woman wearing a niqab.

Inherent to feminist pragmatist thought lies the concept of radical objectivity (Minnich 2005). This ought to appeal to healthcare personnel in that radical objectivity includes subjectivities and intersubjective knowledge building. Medical doctors would be freed from the onerous roles of “knowing best” and expectations of “authoritative” knowledge.

In healthcare, what is, what is known, and what counts for knowledge are questions that are intrinsically interwoven with issues of equity and equality. As this chapter has demonstrated, to do patients justice is no easy undertaking in systems that are driven by other rationales than patients’ best interests. Professional standards, guidelines, as well as healthcare personnel’s own beliefs and prejudice can cause problems for patients, especially for mis- or undiagnosed women. While there are differences in the provision of healthcare globally, there are certain universal truths concerning discrimination against women seeking adequate healthcare, and to some extent these commonalities evolve regardless of women’s backgrounds. Preconceived notions about women’s health are still rooted in historical misconstruing, with western philosophy being as unhelpful in this respect as any other philosophy or cultural expression elsewhere in the world. Medical history and western philosophy have construed some fantastical explanatory models through time. The wandering womb being only one of many explanations as to why women are untrustworthy and intellectually inferior to men.

Knowledge, if regarded as collaborative endeavor and co-produced by applying a relational *and* systems critical approach, can potentially enable robust healthcare relationships to form (Gillberg and Vo 2014; Reid and Gillberg 2014; Cook et al. 2017). If inequalities, inequities, and power imbalances between medical doctors and patients are acknowledged and proactively addressed as problematic, the risk of diverting into more paternalistic concepts and practices of healthcare is minimized. As it makes sense to regard patients as knowledgeable and to assume they wish to live full lives, the need for paternalistic stances let alone the extreme paternalistic can in fact be considered obsolete.

For the sake of debate, however, let us assume patients have no agency and are empty vessels devoid of decision-making skills. An extreme paternalistic approach to patient care would be to tell them exactly what to do based on the medical professional’s assessment of their symptoms. The assessment takes 5 to 10 minutes, and there is no patient voice. Let us assume the patient follows the doctor’s orders stringently, attends therapy sessions religiously, ingests medicines unquestioningly, and then, reluctantly, even guiltily, discovers the therapy sessions do not yield the desired results or that the medicines trigger adverse events. Women are particularly vulnerable to self-blame and will endeavor to self-correct and possibly intimate improvements where there are none. They may also feel inclined to blame themselves for lacking therapeutic success and the ineffectiveness of medicines or any side effects. If they revisit the doctor’s office, it will be reluctant unless their symptoms give cause for alarm. Concurrently, the underlying cause or causes for

their symptoms go unnoticed, deteriorate, and, at worst, cause death. The more educated patients are, the less likely they are to seek medical help (Robson and Lian 2017), so by the time they seek help, months may have passed since the initial symptoms appeared. In addition, a long period of non-/mistreatment may occur due to misdiagnosis or no diagnosis due to the label of MUS. Once a psychogenic label like MUS appears on a patient's notes, they will receive adequate healthcare only with great difficulty, even when presenting with new symptoms (Lian and Robson 2017). It is a feminist pragmatist stance to reject such practices as impractical and unreasonable because they are impractical and unreasonable both for the affected individual and the wider societal context within which these situations unfold. The social fabric of belonging into a caring society is rendered asunder by extreme paternalistic views of women's and men's bodies, but women are more affected by such conduct (see above).

In summary, healthcare urgently requires an ontological and epistemological shift at the paradigmatic level, which is not to confuse different types of knowledge and their specific values with mythical claims about the scientific method as the only valid source of knowledge. Subjective knowledge is not "merely subjective" or inferior to "objective knowledge," and objective knowledge remains elusive while it is infused with fallacies as previously discussed (Minnich 2005). There is a need for radical objective knowledge that comprises all types of knowledge and experience, and failing to provide this for ideologically driven or paradigmatic reasons is unacceptable and detrimental to women's and men's lives (Gillberg and Vo 2014). As emphasized previously, for women, the stakes are invariably higher, and healthcare personnel have the capacity, ability, and power to alleviate suffering beyond examination rooms, patients' notes, and limited appointment times, by rethinking their professional concepts and practices, several of which have been discussed in this chapter.

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Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology

13

Patti Shih

Contents

1	Introduction	224
2	Knowing Culture: Ethnographic Tradition and Critique	226
3	Culture as an Object of Intervention	227
4	Politicizing Culture: Structural Determinants of Disempowerment and Health	228
5	HIV, Marriage, and Mining in Papua New Guinea	229
6	Accounting for Reflexivity	231
7	Blurring the Objective-Subjective Dichotomy and Collaborative Meaning-Making Through Dialogue	232
8	Conclusion and Future Directions	234
	References	235

Abstract

Critical ethnography is a methodological approach to ethnographic research that is explicitly political in its epistemic and empirical focus on challenging power relations and political inequality. It has an epistemic concern about how the notion of “culture” is produced in the research process, through the assumed objective position of the researcher as the “knower” and the study participants as the “known,” and thus taken for granted as a true representation of social reality. This is particularly problematic if this account of culture is integrated into public health programs as an object of intervention and decontextualized from the wider social and political structures that shape inequalities in health and healthcare outcomes. Empirically, critical ethnography attends to an expansive analysis of power relationships, by highlighting issues of social exclusion, marginalization, and injustice in its research focus. The chapter draws on my experience as a

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223

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novice ethnographic researcher in Papua New Guinea, which taught me the importance of understanding structural factors that contextualize the relationship between culture and health, as well as a critically reflexive research position. The chapter discusses how critical ethnography politicizes the interpretive process through a commitment to collaborative meaning-making between researchers and study participants, which enables the social utility of ethnographic knowledge for political action well after the completion of research.

Keywords

Critical ethnography · Ethnography · Epistemology · Culture · Public health research · Interventionism

1 Introduction

It is by politicising culture that we can give it back its meaning and its effectiveness. (Fassin 2001, p. 311)

A foundation of contemporary public health is the assertion that the health and well-being of individuals are contextualized by the social, economic, and political world in which they live. With a humanitarian commitment to health as a human rights and social justice issue, public health interventions aim to proactively prevent disease and improve health outcomes at the population level (Liamputtong 2016). To enable practitioners to devise strategies, policies, and practical solutions to health and healthcare challenges in targeted communities, research methods from a variety of disciplines are used to inform and examine the complex determinants of health. Ethnography, long associated with the research of cultural and social worlds, is a crucial methodology for examining the shared norms and practices of communities of people and provides a nuanced understanding of cultural factors that underscore public health issues (Pope 2005; Liamputtong 2013; see also ► Chap. 26, “Ethnographic Method”).

However, there are practical and methodological dilemmas in the use of ethnography in public health research. In her juxtaposition of ethnographic research as the metaphor of “sitting” and the practice of public health as “doing,” Stacy Pigg (2013) suggests that the lengthy immersion of researchers in the research setting and the careful production of “thick descriptions” of the social world in ethnographic methods can be dismissed by the imperative to efficiently implement solutions and focus on problem-solving in public health programs. Yet, without the thoroughness and nuances about the cultural world produced by ethnographic research, public health interventions can be implemented without thorough engagement with the local community or be less able to unravel the root causes of health problems embedded in social complexities. On the other hand, as Lisa Maher (2002) notes, ethnography traditionally values the objectivity of the researcher, who is urged to maintain a level of scientific detachment from the field and refrain from “contaminating” the analytical interpretation with their own political stance and biases. However, ethnographers uncover so many instances of health inequalities in their

research that the notion of remaining politically neutral in the face of injustice and suffering is deeply unethical and counterintuitive.

There are also *epistemic* questions about the notion of “culture,” one of the most central concepts in ethnography. Episteme is the study of the production of knowledge, and in ethnography this is a concern about *how we come to know* what culture means (Foucault 1972; Rabinow 1986). Critical anthropologists have long interrogated the issues associated with the production of cultural descriptions of a given community by researchers as outsiders, who are assumed to be objective in their interpretation of “culture” and produce an unproblematic account of the social reality of the people they study (see, e.g., Clifford and Marcus 1986; Abu-Lughod 1991). This has direct implications for how “culture” becomes integrated into public health interventions and into the lives of people in the studied communities, which is particularly problematic if the research conclusions do not align with the community’s views and values. Research must be understood as a process that implicates the power relationship between the researcher and the study participants through the production of knowledge. Therefore, a more careful consideration is needed of the interpretive process by which the knowledge of culture is produced through ethnographic studies.

Critical ethnography is an explicitly political methodological approach to ethnographic research methods with its epistemic and empirical focus on challenging power relations and political inequality (Foley 2002; Cook 2005; Madison 2011). It has an epistemic concern about the power relationships that are produced by the research process and prompts a critique of the researcher’s role as the privileged and powerful authoritative voice on “culture” in health and therefore the assumed “truth” of the knowledge made about culture as the ethnographic object of inquiry. Empirically, it analyzes the power relationships engendered within the wider structural contexts that shape health and well-being – that is, the distal social institutions such as political, economic, and legal systems that are less visible in everyday practices but are instrumental in shaping social dynamics and the allocation of social power and resources. Social inequalities are related in part to the epistemic production of knowledge about culture, because the way in which we define and research “culture”. Therefore, by rendering it as an object of public health intervention can disguise the structural power distributions that underscore health inequalities. In view of this, methodology is the key site of a political revolt against current organization of power relationships in critical ethnography (Foley and Valenzuela 2008, p. 288).

This chapter examines the tradition and subsequent critical development of ethnographic research particularly in anthropology and argues how the integration of ethnography in public health thus far has been limited in applying a critical lens on these epistemic issues. In particular, it problematizes the way which culture is often oversimplified as an analytical category to explain ill health and, thus, integrated into public health programs as an object of intervention and decontextualized from the wider social and political structures that shape inequalities in health and healthcare outcomes. It draws on my experience as a novice ethnographic doctoral researcher in Papua New Guinea and illustrates how my learning about culture,

marital customs, HIV risk, and the social impact of mining resonated with my personal experience as the “cultural Other” in my own writing and political voice.

2 Knowing Culture: Ethnographic Tradition and Critique

Ethnography was first used by Western colonial officials and traders to gather information about local populations and their environment under the administration of European empires in the mid-nineteenth century (Madison 2011). In the early twentieth century, anthropologists such as Bronislaw Malinowski and Franz Boas began to establish ethnography as a research methodology characterized by the lengthy immersion of researchers in their research setting, or the “field,” observing and participating in the everyday “natural environment” and activities of a given group of non-Western “Others”. The role of the ethnographer is to capture and write about the observed shared practices and norms of study participants, through developing interpersonal relationships and adopting the language and in some cases, clothing of the local community. As objective “outsiders” looking “inside,” ethnographers are assumed to see the point of view and subjective experiences of cultural Others through their interpretation. The notion of “writing culture,” quite literally the Greek lexicological derivation of ethnography (Liamputtong 2013, p. 148), was born.

The 1920s and 1930s saw further methodological development and refinement of ethnography, as it was extended to examine social marginalization and political inequalities, particularly influenced by the urban ethnography developed by the Chicago School, a group of academics from the Department of Social Science and Anthropology at the University of Chicago (Madison 2011, p. 11; Liamputtong 2013, p. 151) around the time of the Great Depression. The recognition that wider structural factors and notions of power should be integrated into the understanding of culture continued to influence methodological critiques of ethnography well into the 1960s and 1970s. Work in critical anthropology, anti-colonialism, feminism, and intersectional feminism (see for example, Clifford and Marcus 1986; Abu-Lughod 1991) critiqued the notion of “culture” as a colonial invention, constructed to reinforce cultural difference and, therefore, the social as well as political subjugation of cultural Others, and highlighted the subtle reproduction of power and knowledge embedded in cross-cultural research processes.

Critical methodologists in anthropology challenged the heart of conventional ethnography, in particular the notion that “culture” can be “known” through data collection and “written” through interpretation (Clifford and Marcus 1986). These methodologists questioned whether objective research yields the “truth”, and rejected the political neutrality of the researcher as a distant outsider able to develop scientific findings about other people’s culture (Clifford and Marcus 1986; Abu-Lughod 1991; Foley and Valenzuela 2008). In fact, they suggest, the production of knowledge by researchers alone can potentially reinforce the unequal power relations between the researcher as the knower and the study participants as the known (Abu-Lughod 1991; Mertens 2007; Hesse-Biber 2010).

3 Culture as an Object of Intervention

While anthropology has had a long critical engagement with the production of knowledge and power through the ethnographic construction of the cultural Other, in the discipline of public health, “culture” and social determinants did not become a focus until the 1970s. Instead, the more privileged subdisciplines of disease control, public hygiene, and epidemiology dominated. The call to understand the role of culture in public health has been stronger in recent years, as much evidence reveals poor health outcomes are disproportionally skewed by gender, ethnicity, and social, economic, and geographic disadvantage, particularly affecting lower-income communities in developing countries of the global south and so-called “culturally and linguistically diverse” (CALD) communities in developed countries. Social scientists in public health have fought for a more central place in research and urged for an understanding of health that is informed by social research methods and sensitivity to the role of culture (Liamputtong [in press](#)).

However, the engagement of cultural research in public health remains geared toward informing the practical aims of intervention design and complementing the findings of quantitative data with qualitative explanations. From a critical ethnography perspective, the use of culture as an analytical category to explain the determinants of health can run the danger of objectifying culture as a pathological entity. For example, ethnographic research was used to explain the uneven patterns of infection among non-Western communities, gay men, sex workers, and other marginalized groups in early HIV research, which led to the development of epidemiological notions of “risk groups” based on the assumption that the shared norms and practices of a bounded community of people is central to their susceptibility to HIV infection (Glick Schiller 1992; Glick Schiller et al. 1994). By attributing culture to the practice of behaviors that lead to risk and ill health, this explanatory model essentializes a person’s biological destiny to their cultural grouping (Glick Schiller 1992; Briggs 2005; Sovran 2013). The social epidemiological conclusions drawn about the group pathology of certain communities then becomes part of a wider discourse that links ill health to their cultural *difference* to those that are healthy, which further alienates people who are already marginalized and vulnerable to disease.

The influence of an epidemiological vocabulary of causation and effect tends to infiltrate the language and analytical frameworks used in public health social research. The description of culture as a social epidemiological “variable” makes culture a bounded object that can be somehow extracted or inserted into an epidemiological logical equation that explains people’s behaviors and health outcomes. The black and white binary of “barriers and facilitators” is familiarly applied in numerous research projects in culture and health. When translated into interventions, cultural practices that are deemed detrimental to certain health concerns are to be problematized and challenged, but cultural practices that deemed contributing to good health are to be “fostered and promoted” (Taylor 2007; Sovran 2013). At best, culture is integrated into interventions as “cultural competence” or “culturally grounded” education (Wilson and Miller 2003) and, at worse, described as “cultural barriers” or “harmful practices” to be reformed through the rhetoric of “positive cultural change.”

Culture becomes problematized as the cause of illness, as well as instrumentalized as an object of intervention (Fassin 2001; Shih et al. 2017). This is highly problematic from the perspective of critical ethnography, because the knowledge of culture becomes constructed within a positivist framework of cause and effect, conceptualized as a static object open to intervention and malleability. Moreover, when interventions are derived from research evidence produced by external researchers as outsiders and as assumed “experts” with superior knowledge about the essential characters of the culture of study participants, interventions become decisions made *for* recipient communities that do not necessarily reflect their understanding of culture.

Also concerning is that this etiologized analysis of culture is decontextualized from the wider economic and political influences, both current and historical, on cultural patterns and practices. Many of the factors affecting marginalized communities, such as economic vulnerability, violence, and racism, are collapsed into the “less threatening concept of culture” (Gregg and Saha 2006, p. 543), thus the ethnographic nuance of a contextualized temporal social reality is lost.

4 Politicizing Culture: Structural Determinants of Disempowerment and Health

Culture and structural factors are mutually implicated in producing inequality (Metzler and Hansen 2014, p. 128). The everyday experiences of health and well-being are constrained and fostered by social systems, which are in turn produced and reproduced in culture (Cook 2005). However, the role of structure in health is often disguised by the focus on culture as the interpretive lens for health-related behavior. Without understanding the complexities of historical and political power relationships, it is easy to “substitute a political economy of the disease for its cultural and behavioural interpretations” (Fassin 2013, p. 119). Therefore, a politicized understanding of culture is needed.

Indeed, studying culture shows how much culture is itself altered by a history of social inequality beyond the level of everyday behaviors and practices. A study of African-Americans’ dietary patterns (Airhihenbuwa et al. 1996) revealed that a diet high in fat and salt, contributing to a range of significant chronic health conditions, was recognized by study participants as stemming from their ancestral history of slavery and economic disadvantage, yet is continued today by both higher- and lower-income African-Americans, as these food patterns are absorbed and socialized into a part of their shared understanding of a “black culture.” However, the response of food patterns to structural and environmental influences remains evident today, according to the study, as it revealed that psychosocial vulnerability to institutional racism and the direct marketing of fast food to African-Americans impacted on diet and health. This suggests that successful behavioral change to healthy eating is a cultural issue that will also depend on challenging the structural vulnerability to these factors.

The collection of ethno-specific health data, whether in developed countries or globally, reinforces the assertion that people of certain ethnic origins are susceptible

to different patterns of health and illness. Yet, the experience of socioeconomic discrimination along ethnic lines that are both current and historical, and relevant in both the global north and global south, is not properly accounted for in explaining the social disparities in accessing healthcare, education, housing, and other social resources pertinent to good health. The historically produced notion of ethnic difference reinforces pre-existing social hierarchies and legitimizes the division between the powerful and the powerless. This also applies for gender-specific health research and the way which women are portrayed as biologically distinct to men. Inhorn and Whittle (2001) explain that the historically male-dominated scientific knowledge of biomedicine and epidemiology amplifies women's difference to men in terms of health, when sexual difference is used to account for disease prevalence and lifestyle risk factors. In fact, historically, men and women and whites and non-whites are rarely studied together as the same group in clinical trials (Inhorn and Whittle 2001). Rather than suggesting a sense of sameness, people are differentiated and analyzed separately in populations along the blanket categories of sex and ethnicity.

Through the objective production of knowledge about cultural Others, "women, blacks and people of most of the non-West have been historically constituted as the other in the major political systems of difference on which the unequal world of modern capitalism has depended" (Abu-Lughod 1991, p. 54). The patterns of social marginalization that are linked to historical domination of the powerful over the subjugated suggest that the very construction of "culture" as an explanatory category for behavior is a way to normalize the continued marginalization of the less powerful from the "fruits of scientific and social progress," as expressed in Paul Farmer's concept of structural violence (2001, p. 79). As Farmer eloquently argues, "sickness is a result of structural violence: neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency" (Farmer 2001, p. 79).

By politicizing the understanding of culture using the lens of structural inequality and its link to the production of knowledge about cultural difference, critical ethnography makes a link between its empirical and methodological concerns about unequal power relationships and social justice.

5 HIV, Marriage, and Mining in Papua New Guinea

The experience in my own research about culture and its interpretive process also taught me lessons about the importance of understanding structural factors that contextualize the relationship between culture and health.

My ethnographic research in Papua New Guinea examined faith-based HIV prevention programs and the influence of religion and culture on sexual and reproductive health. Initially, it had little focus on structural inequality. However, my fieldwork began in 2011 at the height of a mining boom. In one rural township field site, a Liquefied Natural Gas project was underway to construct a 700 km pipeline to deliver liquefied natural gas from the Southern Highlands extraction site to a processing plant in Port Moresby. It was hailed as the bastion of economic

development for the country in the twenty-first century and was a significant part of everyday life in the area. Initially, I was unclear about the role and impact of mining in the big picture of healthcare and HIV. As a novice researcher, I went about observing everyday activities of my study participants, who were healthcare workers from a well-known local faith-based healthcare service, by going to clinics; watching practices; mapping outreach fieldwork, which sometimes meant hiking for hours over difficult terrain to reach remote villages; attending antenatal clinics; cooking; socializing; gardening; and going to evening prayers and attending church in the Southern Highlands community where I lived.

As I began to interview and talk more in-depth to study participants, there appeared to be a firm consensus about the cause of HIV (see expanded discussion in Shih et al. 2017). Faith-based healthcare workers deemed polygyny, the marital practice of a man marrying multiple wives and paying a bride price of material and money to the bride's family to compensate for the loss of her labor, as a "harmful tradition" and a "bad" kind of culture in the area. They believed polygyny, as a type of sexual concurrency, increased HIV risk among men and women, and the exchange of bride price further commoditized women and put them more at risk of gender-based violence and forced sex. Their assertion was reflected by policy documents, training materials, and donor-sponsored research reports used by healthcare workers, which all featured an assertive language that problematized cultural practices such as polygyny and bride price exchange as "bad" traditions that should be thoroughly discouraged to prevent further HIV spread.

However, there was also a concurrent counter-discourse about culture. The same healthcare workers also explained that in present day Papua New Guinea, traditional polygyny and bride price practices have changed, particularly with the introduction of the cash economy. Polygyny was once only available to tribal leaders, usually older men who have acquired resources such as land and pigs for bride price payment. However, with the economic opportunities provided by the mining project today, younger men were also more able to afford bride price payment. With the increased cash flow to more men and to younger men, the practice of bride price has increased and its average worth inflated. The occurrence of other forms of sexual concurrency, such as transactional sex, has also increased. Moreover, healthcare workers were most concerned that the traditional kinship relations and social obligations that were once cemented by traditional marriage and bride price exchange had been replaced by individualized forms of sexual transaction and monetary acquisition. The availability of cash meant that the cultural values of reciprocity and the social safety net that were once provided through inter-clan marriages and bride price exchange were replaced by individuals' ability to obtain financial and material wealth.

It was the loss of kinship obligations and social fabric attached to traditional practices of polygyny and bride price exchange that was lamented by healthcare workers, which they associated with cultural breakdown and lack of social cohesion. Ironically, HIV infection is blamed on polygyny as a "harmful tradition," when in reality, contemporary concurrent sexual relationships in Papua New Guinea, whether in married forms or not, have been significantly reconfigured from traditional forms due to economic and social change. In fact, polygamous practices had been

problematized by Christian missionaries and colonial officials since their arrival in Papua New Guinea in the late nineteenth century, which was the basis for the further changes to marital practices today, under the influence of social and economic change. However, many types of sexual concurrency, whether in informal or married partnerships, are still labeled as “polygyny” by healthcare workers.

Having started to make sense of the intersection between the changes in the local political economy impacting marriage and sexual networks, I began to see things that I had not given much notice before – like the number of large trucks and broken roads on the region’s highway, the abandoned site of a labor camp just outside town, the new airport in another township parked with giant cargo planes that looked out of place, and young men in the back of mini buses sauntering toward work camps. I noticed women were mostly excluded from such economic opportunities and that many of these young women have become much more vulnerable economically and sexually in the wake of this change.

This was a complicated story about culture that healthcare workers themselves already knew but did not articulate in the healthcare language in which they were trained. The donor-driven prevention programs they practiced mostly concentrated on discouraging individuals from participating in cultural practices such as polygyny and bride price exchange. The key focus remained on individual behavioral change and HIV awareness education as the ultimate solution to HIV risk, and not on challenging structural influences such as economic inequality and social change that can shape sexual practices. The structural complexities of HIV were drowned out by an intense focus on “culture” as the cause of illness, when in reality, so-called traditions have long been altered by almost half a century of missionization, colonization, and economic development.

6 Accounting for Reflexivity

During my fieldwork, it became apparent there were two different stories about culture: one about culture as object that causes illness and thus must be discouraged, and another about culture as subject about losing the meaning of society and kinship. In reconciling these two stories, I came to see a broader story about health that is intertwined in culture, economics, politics, and history. I realized it was not “their culture” in Papua New Guinea that I was documenting, but rather I was conveying an experience of loss. It reminded me of the opening passage of Renato Rosaldo’s article (1988), in which he evoked the notion of “people without culture”: We often question the authenticity of what we regard as appropriate representation of culture – temples, museums, costumes, rituals, dance; things that are beautiful, to be held and admired, not spaces left empty and hearts left broken. But, perhaps it is the reason why we find them empty and broken which most triggers critical ethnographers.

Much later after my fieldwork, I understood why I saw a story about culture and its connection to structure and history and chose to make sense of culture in this political way. Cultural dispossession and cultural fluidity was also an experience in my life and that of my own family. This is another story from another time and place,

about my experience of migration and cultural dislocation. As a child, I moved from my native Taiwan to New Zealand in the early 1990s. The haunting feeling of disconnectedness from my cultural roots and making sense of my own cultural and racial difference to the New Zealand children around me will always stay. But this experience also includes the resilience of Taiwanese language and culture under attack during Japanese and Chinese occupation in my grandparents and great-grandparents' lives many decades earlier. The contestation of a rightful Taiwanese identity is passed down as family stories; my aunts tell of being fined by Chinese officials for speaking Taiwanese at school during Chiang Kai-shek's authoritarian rule; and my grandfather tells of hiding in a cellar to avoid Chinese persecution during the 228 Massacre of 1947. These are legacies of resistance and survival, shared by several generations of Taiwanese people, which propel me to assert my right to belong, speak, live, and work in a multicultural Australia. It will always be part of my research interest in culture and health and my political activism. There will also always be a constant agitation about the fluidity and uncertainty of my own identity. These are the same questions my study participants in Papua New Guinea asked themselves: *Who am I, what am I, what is my culture?*

My experience in Papua New Guinea encouraged a different way to think about researcher reflexivity. As the ethnographer of an account of cultural dispossession that contextualized health and illness, my personal familiarity with cultural fluidity triggered a sense of solidarity with my study participants and led to focusing the study analysis on a historical and structural account of power and inequality. Reflexivity is less about declaring how pre-existing experience and prior understanding of the topic influenced how data was interpreted objectively (the "whole truth") but rather taking ownership of the researcher's subjectivity as part of the production of research knowledge (the "partial truth") (see also ► [Chap. 26, "Ethnographic Method"](#)). Critical ethnography values the researcher's subjectivity in shaping the explicitly political angle that the data takes. Of course, this is not to suggest that other researchers with a different experience of culture than I would not have drawn similar conclusions about culture vis-à-vis structure, but that this was the particular way which I did, and found a specific and deeply personal pathway to discovery.

7 **Blurring the Objective-Subjective Dichotomy and Collaborative Meaning-Making Through Dialogue**

Reflexivity in critical ethnography challenges the strict divide between the objective and subjective positionalities taken by the researcher and study participants. This component of critical ethnography contests the dichotomy between the objective positions of the researcher as the "knower", making knowledge about the study participant as "the known", which subsequently reproduces the power relationship between them. As Madison (2011, p. 7) suggests, "positionality is vital because it forces us to acknowledge our own power, privilege and biases just as we are denouncing the power structures that surround our subjects."

To challenge the inequality stemming from the production of knowledge through the object/subject divide, a more collaborative approach to knowledge-making with study participants is required. The ethnographer entering the field and engaging with study participants is the coming together of lifeworlds. Study participants are not the cultural Other as a static representation of the ethnographic present but part of the production of ethnographic knowledge through dialogical interaction with the researcher.

However, this is not dismissive of the objective view of the research scenario. Fassin (2013) argues that the objectivity of an outsider is precisely the sharp analytical tool to examine the things that study participants themselves “cannot see or prefer to ignore” (p. 123), such as identifying and questioning the local politics and controversies which they are themselves involved and implicated in, which only the emotional distance and intellectual neutrality of strangers can offer (p. 124). Thus, the objective perspective provides a corroborative and contextualized nuance to the subjective accounts. van Meijl (2005) suggests that critical ethnographic positionality is about a degree of flexibility in shifting from the objective to the subjective *and back* by maintaining an agnostic disposition, one that can occupy both the spaces and perspective of the objective and subjective view, as both outsider and insider.

An objective but reflexive critical ethnographic account of a researcher should aim to *evoke*, rather than *explain* the lived experience of others (Foley 2002), as prescribed in the notion of bearing witness (Foley 2002). The ethnographer stands in solidarity with study participants and makes visible the injustice of a complex and often historically produced experience, yet does not intrude in making conclusions or offering solutions as an outsider. This is a stark departure from the common practice in aid and development programs where outsider-external expert-driven interventions are carried out without thorough engagement with the subjective view. Rather than intervening *on behalf* of subjects or *speaking for* participants, bearing witness is *speaking from* the ethnographic location in which study participants are situated.

There is much diversity and difference in how ethnographers chose to engage in political activism with study participants, ranging from active and deep collaboration in political movements to the more removed yet stoically provocative stance of bearing witness (Foley and Valenzuela 2008). Fassin (2013, p. 125) suggests that the “social utility” of ethnography is that it offers a critical thinking of a complex political problem, by translating it into a language that makes sense for taking political action. Thus, ethnographic research can continue beyond an academic exercise after the completion of research activities by becoming a resource for knowledge and action. I was heartened to find my research results cited by a Papua New Guinean activist website aimed at challenging the political and economic injustices of mining in their country and tweeted by a Melanesian women’s interest group. After I returned to the study site to report and discuss my research with the study participants upon the completion of the project, the results were conveyed and shared in the local church community newsletter, which in turn encouraged more local healthcare workers to correspond on the issues with me. The research, I hope, will add to the body of knowledge for taking political action and make critique about the suffering of HIV as part of the injustice structural violence, as new generations of researchers are inspired by and inherit the knowledge that came before them, such as

the political and critical commitment established by early ethnographers in HIV research such as Paul Farmer and Philippe Bourgois.

Returning to Pigg's (2013) metaphor of "sitting" and "doing," her argument that "sitting" is absolutely an action rings true. Ethnography diagnoses the core problems of health, not on the surface for the purpose of a superficial intervention, but at its structural and historical core. As a method, therefore, it has a much longer lasting and political potency. Indeed, the critical ethnographic method of "sitting" is by far not a passive kind of research.

8 Conclusion and Future Directions

We come to know "culture" through the ethnographer's interpretation; thus the researcher and their analytical lens are pivotal and exceptionally powerful (Madison 2011, p. 4). Critical ethnography does not seek to replace conventional ethnography – as the commitment to thorough immersion and situating knowledge in a social contextual-specificity remains its core. Rather, it cautions the dangers of an "uncritical" ethnography used in public health research that renders culture a pathologized object of inquiry and intervention. It is a critical recasting of ethnography's methodological commitment to equality and social justice, which requires challenging the researcher's role as the sole and objective producer of cultural knowledge in the "writing of culture," by transcending the objective/subjective divide in research positionality.

Likewise, critical ethnography does not seek to abandon culture as a key analytical concept in public health research but rather to approach culture more carefully in its epistemic construction and in its wider historical and structural context. As Metzl and Hansen (2014) suggest, a move from *cultural competence* to *structural competence* in healthcare recognizes that culture matters in recognizing the social diversity of communities and healthcare needs, but also that structure contextualizes the power relationships enmeshed in cultural representation of the vulnerable and marginalized and thus shapes many healthcare outcomes (see Liamputtong *in press*). The first step in structural competence for public health practitioners and researchers is training the critical eye to recognize structural aspects of health and illness and developing the critical voice to articulate the representation of the cultural in the complexity of structure (Metzl and Hansen 2014).

The future of critical ethnography is about being resilient to the challenges in the current climate of social sciences and health research, when qualitative research in general is already disadvantaged in funding and recognition (Denzin and Giardina 2008; Greenhalgh et al. 2016). There is increasing pressure from funding bodies for researchers to produce implementable and translatable results, with assessment and evaluation criteria measured on the deliverability of tangible results ("How many condoms were provided this month? What percentage improvement to Knowledge-Attitude-Behaviour on HIV this year?"). These benchmarks reflect what Pigg (2013, p. 128) describes as the milieu of the "neoliberal ethic of speed and efficiency that has become normalised, and moralised, in the ways global health activity makes

things happen,” in the expense of the rigor required to identify the root issues of vulnerability and disempowerment in health. The shrinking time and resources allocated for fieldwork reduces the thoroughness of ethnographic immersion and the capacity for relationship-building between researcher and participants and, thus, the quality of research. This increases the risk of research participants becoming simply sources of information, which makes the research process more exploitative and less equitable and collaborative. This concern was emphasized by a healthcare worker in a busy urban clinic in Port Moresby, as we were having a cup of tea in the staff room one afternoon (Shih 2015, p. 44):

I think it's good that you're here all the time and just relaxed about it, I don't like it when some researchers come right on time at like 10am and expect us to be ready to talk to them and then leave after that. It's good you're just hanging out and eating with us.

From a logistical perspective, ethnographic methods provide ways for the researcher to generate trust and minimize the coercion and time pressure placed on healthcare workers in their participation in the research project. But, thinking about it in terms of culture and the wider context of promoting equity and sharing the production of knowledge, it elucidates a cultural discord between the Western notion of work ethic and punctuality and the local approach to what seems a chaotic, elusive yet surprisingly productive “PNG time.” Has research become such a precious process that study participants do not receive some time and patience and allowed to do what they do in the very social setting that researchers are trying to understand?

The future of critical ethnography relies on researchers remaining resilient and committed to their critical voice, in both methodology and the politics of research, in the face of increasingly diminishing space and time for research.

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Empathy as Research Methodology

14

Eric Leake

Contents

1	Introduction	238
2	What Is Empathy?	239
2.1	Interdisciplinary and Debated Approaches to Empathy	240
2.2	Modes of Empathy	241
3	Components of Practicing Empathy	243
3.1	Perspective-Taking	244
3.2	Cultural and Contextual Awareness	245
3.3	Communication, Listening, and Collaboration	247
3.4	Self-Reflection and Critical Empathy	248
4	Limitations and Risks of Empathy	250
5	Conclusion and Future Directions	251
	References	251

Abstract

While a long-standing concern in psychology and philosophy, empathy is receiving increased attention in the social sciences for its importance in interpersonal relationships and its use in cross-cultural contexts. I begin this chapter with a brief history and overview of the concept of empathy as a means of understanding the perspectives and experiences of others. I then consider the features that distinguish empathy and the modes through which empathy functions. I address empathy's value across disciplines and extend the application of empathy to the health and social sciences by outlining how practices of empathy might work as a component of research, especially in consideration of different perspectives and social conditions. I apply practices of empathy to research site and participant selection, communication, collaboration, self-reflection, and the recognition of limitations.

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237

I advocate the practice of critical empathy, in which researchers acknowledge the biases and shortcomings of empathy while simultaneously looking to establish shared goals and interests. To conclude this chapter, I consider the continued necessity of empathy as a component of research despite empathy's limitations.

Keywords

Empathy · Psychology · Philosophy · Perspective-taking · Biases · Cultural awareness

1 Introduction

Empathy is rooted in what it means to be human. Primatologist Frans de Waal (2009) argues that empathy is not only part of human nature but part of our natural ancestry. He has observed what he considers empathy in chimpanzees and the ways that they relate to one another. Empathy all starts and coincides, de Waal argues, with maternal care. Referencing hopes for greater cooperation and social responsibility, he calls empathy “the grand theme of our time,” although, admittedly, the promise of empathy now seems strained (p. ix). Even with the long-standing biological lineage detailed by de Waal, empathy is a relatively new concept, as the word *empathy* does not enter the English language until the early twentieth century when it is introduced from the German *einfihlung*, literally “feeling into” (Edwards 2013). Empathy speaks to the ways that we communicate and relate to one another, the cognitive and affective aspects of interpersonal understanding, the moves that we make in order to arrive at a fuller understanding, and the risks inherent in making such moves, loaded as they are with potential for biases.

Attention to empathy has increased in recent years across disciplines, as both an area of inquiry to itself and as a means of training practitioners. Psychologists and neuroscientists, for example, are studying the motivational nature of empathy (Zaki 2014) and how it functions in the brain, especially as related to so-called mirror neurons (Iacoboni 2009). Work in narrative medicine aims to teach physicians to be more empathic in their interactions as they listen to the stories and concerns of patients (Chen et al. 2017), social workers are being taught ways to more empathically respond to the needs of their clients for the purposes of social justice (Gerdes et al. 2011), and anthropologists are exploring the promises and limitations of empathic research practices as well as researching what empathy means in different cultural contexts (Hollan and Throop 2011). Scholars in the humanities are investigating the effects of empathic reading and writing practices (Keen 2007), while educators at all levels are considering how their teaching might increase prosocial activities and dampen bullying and other negative behaviors. And the list goes on. Some of the growing interest in empathy may be attributed to the discovery of mirror neurons, although the significance of that discovery and its potential for explaining interpersonal human interactions have been questioned (Gruber 2013). Some of the interest also likely reflects contemporary public concerns regarding social division, widening inequalities, forces of globalization, and the possibility of understanding one another across personal and cultural differences.

Empathy is useful conceptually and methodologically because of the very concerns that make it so prominent at this moment. There are significant risks to empathy, such as in empathic biases, but those risks are pre-existing; responsibly employing empathy helps to acknowledge and mitigate those risks. As will be detailed in this chapter, empathy is not a methodology to itself but a component of multiple methodologies. A greater empathic awareness highlights the position of researchers, the position of the research participants and area, and the place, social context, and relationships among them. In this chapter, I first survey interdisciplinary concepts of empathy and the significance of the term as it has developed through history and across fields. I distinguish empathy from the related concept of sympathy and break empathy into constituent modes. I then describe components of practicing empathy in research and interpersonal interactions, including the practice of perspective-taking, cultural awareness, dialogue, and the critical empathy. I acknowledge the risks and limitations of empathy, arguing in the mode of rhetorician Dennis Lynch (1998) that empathy is valuable in part because of those risks and how it brings them attention. I conclude with some thoughts on the possible future of empathy as a component of research.

2 What Is Empathy?

Much scholarship on empathy starts with just this question, of what empathy is, because empathy is an ambiguous term. To get right to it, the most complete definition of empathy, I think, is that provided by philosopher Amy Coplan (2011, p. 5): “Empathy is a complex imaginative process in which an observer simulates another person’s situated psychological states while maintaining clear self-other differentiation.” As Coplan explains, when she says that empathy is complex, she means that it includes affective and cognitive components. When she says that it is imaginative, she means that it requires the observers to make some assumptions concerning the other person. And when she emphasizes a “clear self-other differentiation,” she does so to underscore the importance that a person keep in mind that “I am not you, and you are not me” even while using empathy as a way of approaching the understanding of somebody else.

Our contemporary concept of empathy originates in eighteenth-century German aesthetic philosophy with the term *emfühlung*. In her conceptual history of *emfühlung*, Laura Hyatt Edwards (2013) notes that the root, *föhlung*, means “to grasp, comprehend, or know with certainty through touch” (p. 271). It was used to theorize our physical responses to art and objects. *Emfühlung* was translated to empathy and introduced to English by psychologist Edward Titchener in 1909. He uses the term to describe how concepts may be felt or acted in the “mind’s muscles” (cited in Edwards 2013, p. 276). With Titchener’s use, empathy transitions from aesthetic philosophy to psychology and becomes more concerned with interpersonal relations. Definitions of empathy since have proliferated, as empathy often is lumped together with sympathy and compassion. To help define empathy, it is useful to distinguish it from sympathy, one of its closest lexical relatives.

Sympathy often is used interchangeably with empathy, although empathy is currently more the vogue of the two, seeming, I assume, more sophisticated and less sentimental due to its basis in psychology. Both sympathy and empathy have similar Greek etymologies as “with” or “in” “feeling.” The primary distinction is in perspective and positioning relative another. While sympathy is considered feeling *for* another, empathy is better understood as feeling *with* another. Philosopher Arne Vetlesen (1994, p. 148) distinguishes the terms by defining empathy as “humanity’s basic emotional faculty, a specific manifestation of which is sympathy; being a particular feeling, sympathy is facilitated by the basic faculty of relating to others, which I term empathy.” We have then a definition of empathy distinguished from sympathy in which empathy is primarily reactive to the situation of another and precedes sympathy. Empathy in this formulation is the basic way that we relate to one another prior to and including making a commitment based upon that relationship.

The concept of sympathy building upon empathy adds an important emphasis at the level of commitment leading to action. This is evident in the explanation provided by philosopher Douglas Chismar (1988, p. 257), who writes of the difference between empathy and sympathy:

To empathize is to respond to another’s perceived emotional state by experiencing feelings of a similar sort. Sympathy, on the other hand, not only includes empathizing, but also entails having a positive regard or a non-fleeting concern for the other person. . . A ‘sympathizer’ is one who goes along with a party or viewpoint, while an ‘empathizer’ may understand, but not agree with the particular cause.

This is a critical distinction. A researcher may empathize with a participant’s beliefs or positions without necessarily supporting those beliefs or positions. Sympathy, however, results being persuaded to another’s view or cause, so that in witnessing another’s situation, one not only understands that situation but aligns oneself in order to amend the situation.

2.1 Interdisciplinary and Debated Approaches to Empathy

I want to collect here a few more interdisciplinary understandings of empathy in order to round out the concept. Literary scholar Suzanne Keen (2007), for example, defines empathy as “a spontaneous sharing of feelings, including physical sensations in the body, provoked by witnessing or hearing about another’s condition” (p. xx); and as “the spontaneous, responsive sharing of an appropriate feeling” (p. 4). There are three important elements to this definition: that empathy is spontaneous, physical, and provoked by another’s situation, in witnessing or hearing about it. Empathy works across differences and distances, which is an important quality of folklorist Amy Shuman’s (2005, p. 4) theory and critique of empathy. She starts with her definition of empathy as “the act of understanding others across time, space, or any difference in experience.” Psychologists and common experience tell us that we most readily empathize with those whose presence is immediate: the person on the

street, our neighbors and colleagues at work, the friend, or family member. If somebody cannot be present, then the more visceral the sight or the sound and the more felt the emotion – the closer they come to being present – the more powerful the empathic identification. But presence is not a requirement, especially in an age of immediate audio and visual communication.

One of the more influential approaches to empathy is that of developmental psychologist Martin Hoffman (2000, p. 4), who defines empathy generally as “an affective response more appropriate to another’s situation than one’s own.” Like others, Hoffman is defining empathy as the approximation of congruency between one’s own and another’s response to a situation or inner state or feeling. There is a shared perspective and common humanity here. This quality speaks to necessary relationships of selves and others that are always already a part of empathy. The other important quality of Hoffman’s definition is his emphasis on the “affective” as characterizing the type of response one has in empathy. Through this emphasis attention to empathy can be read alongside the larger shift of attention to affect throughout the humanities and social sciences. Hoffman’s focus on affect does not mean to relegate empathy to the purely emotional. Instead, he works to do just the opposite in explaining how empathy works as part of larger cognitive processes that combine principles with emotional charge. He writes of what empathy brings to cognitive processes in terms of pairing the more immediate and felt charges of empathy with the more abstract and considered workings of moral principles. This is at the center of his work on empathy, as empathy gives affective force to the support of moral principles.

The role of empathy in the development of morality is somewhat debated. Psychologist Paul Bloom (2016) has forcefully argued that empathy is a not a reliable moral guide because of the biases to which empathy is prone. He instead advocates rational compassion. Bloom defines empathy as “the act of coming to experience the world as you think someone else does” through feeling what you think other people feel (p. 16). He distinguishes between “emotional empathy” and “cognitive empathy,” with his critique focused more upon emotional empathy; he views cognitive empathy as a morally neutral tool for understanding, one employed by fair-minded judges as well as psychopaths. Bloom allows that empathy is great for the arts and for intimate relationships and that it can push us to do good, “but on the whole it’s a poor moral guide” (p. 2). His division of emotional (or affective) and cognitive empathy is contested, however, as many scholars consider empathy to involve both processes, as noted above with Coplan’s definition. Those who promote the moral as well as social and epistemological values of empathy, such as psychologist Jamil Zaki (2017), tend to view empathy as both cognitive and affective, each part of the process counterbalancing and informing the other.

2.2 Modes of Empathy

Empathy is possible through multiple modes. Those are generally broken into two groups, the first being the nonverbal and automatic and the second being those that

occur through more of a mediated process. Hoffman (2000), for example, outlines what he determines as the five modes of empathic arousal. three of which are preverbal and involuntary for the most part, those being mimicry, conditioning, and association. Two of the modes are what Hoffman (2000, p. 5) calls the “higher-order cognitive modes” of mediated association and role or perspective-taking. All of these modes are useful for a full accounting of empathy, and they can work together to reinforce one another in interpersonal encounters and in more purposeful exercises of empathy. Here, I will outline some of the most important modes of empathy for research processes in both interpersonal encounters and through mediated means.

Our earliest experiences with empathy occur through nonverbal automatic modes as infants. Empathy may be experienced as a form of affective contagion. Babies, for example, can start crying when they hear other babies crying. The babies did not hear another baby cry, determine that the other baby is sad, and then decide to share in that sad baby’s emotional experience. Rather, they pick up the cry and begin to cry as well, sharing the sad baby’s experience not through a purposeful perspective-taking but through physical affective feedback, in which their bodily response to their own crying produces a sense of being sad. It may be that, similar to the emotional model proposed by William James, they are not crying because they are sad but are sad because they are crying. Affect is frequently credited as being picked up physically in this sense, so that we adopt one another’s mood in a somber room and pick up one another’s excitement at a concert, thereby experiencing a charged but not always clearly articulated type of affective empathy.

Facial expressions and mimicry work in a similar mode to that of contagion. We often pick up the facial expressions of others, sometimes when looking at visual representations of other faces but especially in interpersonal encounters. The same can happen with body positions generally. So, if I am sitting with a group of people and many in the group are smiling, I may be more likely to smile as well. When talking with another person, I may be more likely to appear despondent if that other person appears despondent, as I mimic the other person’s facial expressions. Sometimes people will even begin slightly to mouth the words that the other person is saying as the other speaks. The mimicry of these facial expressions also may provide a sense of affective feedback, so that I begin to take on not only the expressions but also some of the feelings of the other person. This happens automatically, without a person purposefully setting out to mimic another’s expressions and feelings.

The mediated modes of empathy refer to those that generally depend upon intentional language use. When somebody reads or hears about another’s experiences and empathizes, this is empathy through mediated means. We also experience this form of empathy when engaged with fictional narratives, whether in reading novels or watching films, which may also simultaneously engage in automatic empathy through their visual and affective cues. Two key modes for mediated empathy are association and perspective-taking. In mediated association, one person might read or hear about another person’s experiences and feelings and remember when they felt likewise, drawing upon their own experiences and associating those feelings with the other person (Hoffman 2000). This is a direct communication of what somebody is feeling, but it depends not simply upon automatic visual cues but

meaning as communicated through language, although that communication also can conjure simultaneous visual representations (Hoffman 2000). When perspective-taking, a person imagines what it would be like to be in the position of another. The other's feelings in this sense may be more implied, more the result of the perspective-taking, than a direct communication. Perspective-taking depends upon the imagination and drawing from one's own experiences while also attending to the experiences of somebody else. Perspective-taking can be a tricky balance between self and other. I will further detail perspective-taking later. Finally, Keen (2010, p. 80) proposes what she calls "situational empathy," a type of perspective-taking that arises out of narrative. In this case, a reader imagines themselves in the situation of a character and maybe remembers being in a similar situation. This mode of empathy depends more upon contextual factors than it does the personal experiences of another. The situation rather than the individual is the key factor here. Although Keen's focus is literary narratives, this mode of empathy may be experienced outside of literature when we rely primarily upon situational cues, rather than personal cues, in empathizing with somebody else. Such a situational empathy is weak in how it responds to the experiences of another, but it does highlight the power of particular settings and contexts.

These modes of empathy apply to multiple research situations. A researcher, for example, may find themselves picking up the feelings, moods, and expressions of others. This type of automatic empathy can make interpersonal and group research situations more comfortable, as participants feel as though they are on the same page with one another. It can also create a sense of solidarity that includes the researcher, who should take care not to use empathy and group cohesion to mislead participants in any way, such as by allowing them to misconstrue the role of the researcher. Maintaining a clear sense of role, along with a concern for the well-being of participants, is critical for the researcher. Automatic forms of empathy are helpful so long as they support those efforts. Automatic modes of empathy also highlight the importance of setting and the context for interactions in research. Some work may be more effectively done through direct interpersonal interactions rather than mediated communications. Awareness of the mediated modes of empathy can be valuable in the composition and presentation of research, as empathizing with research participants can help others better understand their situations, values, concerns, and motivations. Effective researchers are also effective communicators and may do well to learn how to responsibly employ some of the techniques of narrative empathy. Responsible empathy often is a component of the most ethical efforts in telling another person's story, thereby better serving the interests of the research participants, the researchers, and the readers.

3 Components of Practicing Empathy

Practicing empathy as researchers, and including empathy as a component of any particular research method, requires a balanced awareness of oneself, one's research participants, and the research situation. This multiple attentiveness can be difficult,

as the points of awareness can be in tension. In this section, I detail the moves and considerations that may assist in practicing empathy as a researcher.

3.1 Perspective-Taking

At first, the practice of perspective-taking can seem relatively simple. We have practice in it all of the time, when we try to think about what somebody else might be thinking or feeling. Actually implementing perspective-taking, however, is much more challenging, particularly in balancing a focus on self and a focus on another.

Perspective-taking is often divided into two categories, self-focused perspective-taking and other-focused perspective-taking. Self-focused perspective-taking is that in which you imagine what it would be like if you were in another person's situation. It is the practice, as the saying goes, of putting yourself in somebody else's shoes. This is the most common form of perspective-taking and tends to be the easiest. We are pretty well equipped at imagining what we might think and how we might feel in another situation. Self-focused perspective-taking can be affectively powerful (Hoffman 2000). As we imagine ourselves in another's situation, we begin to access our emotions and start to feel how that situation might affect us. But while self-focused perspective-taking gains in affective charge, it loses in accuracy. The way that I might feel in a situation could be very different from the way that somebody else might feel in a situation, given our differences in life experiences, values, concerns, preferred outcomes, and so on. Self-focused perspective-taking makes the exercise all about me. This also leaves self-focused perspective-taking liable to what Hoffman (2000, p. 198, 59) calls "empathic overarousal" and "egoistic drift." In empathic overarousal, my sense of distress at the suffering of another, combined with my own my anxieties and emotional state, can become so intense that I shut off empathy altogether, such as by turning away from the other. In egoistic drift, while empathizing with another, I become so absorbed in my own experiences and emotional responses that I begin to focus more on myself and less on the experiences and emotions of the other person until my empathic response becomes all about me. These liabilities demonstrate the limitations of self-focused perspective-taking, although it remains useful for its emotional power. Self-focused perspective-taking falters the greater the differences between somebody else and myself. If as a researcher, I happen to be working with research respondents who are very much like myself in experiences, values, cultures, and so on, then self-focused perspective-taking could gain accuracy. That degree of similarity is unlikely, however, in most research contexts.

Other-focused perspective-taking tends to be much more accurate but less emotionally charged. For a researcher, this is a positive trade-off. Other-focused perspective-taking asks that you not imagine yourself in the place of another but instead imagine what it is like for that other person in that other person's place. To do so requires knowing more about the other person's experiences, interests, emotions, cultural contexts, desires, and anything else that makes that other person who they are. To successfully practice other-focused perspective-taking, a researcher needs to spend time talking with and getting to know the research participants. Paying

attention to context clues and other details can be helpful, too. Other-focused perspective-taking makes it more difficult to make assumptions about another person, as attending to the particularities of that other person and their situation creates fewer opportunities for assuming as a way of filling in the gaps. A helpful variation of other-focused perspective-taking proposed by Hoffman (2000, p. 297) is “multiple empathizing,” in which a person imagines how somebody close to them would fill in the position of another. The person might choose somebody close to them, somebody who they know relatively well, who is most like the person they want to empathize with. By empathizing with another by imagining a closer friend or relation in that other’s place, one could gain some empathic accuracy alongside emotional force, since imagining somebody close to you is easier and more emotionally engaged. This could be a useful move in those situations when a researcher needs an empathic shortcut because of time or other limitations.

A successful practice of perspective-taking frequently will employ both forms, self-focused and other-focused perspective-taking, simultaneously. In doing so, one may draw upon one’s own experiences and emotions while also attending to the realities of the other person. This type of dual perspective-taking is what philosopher Martha Nussbaum (2001, p. 328) calls a “twofold attention,” borrowing a term from Richard Wollheim, in which one imagines both the self and another in the other’s place, all the while keeping in mind the clear distinction between self and other, as underscored in Coplan’s definition. The tension between self-focused and other-focused perspective-taking is never static. It is always moving as attention shifts more in one direction or another, particularly in more emotional situations. The cultivation and reliable employment of a twofold attention, one with an awareness of the tensions and shifts in either direction toward self and other, is a valuable skill for a researcher who wants to employ empathy as a component of the research process.

3.2 Cultural and Contextual Awareness

Empathy as a conscious process requires the basic assumption that we might begin to approximate the perspectives, feelings, and experiences of another. For example, in other-focused perspective-taking, how might one start to assume how another feels in a situation unless one assumes to have some shared access to what another might feel? These are always dangerous assumptions. Assumptions of commonalities are safest when one is attempting to empathize with another whose background and experiences are closest to one’s own. But, even then, they are quite risky, because similarities of background and experience do not necessarily or even generally lead to shared affective states. The inherent risks of these assumptions contribute to the familiarity bias in empathy. It is generally the case, for example, that empathic identification with a sibling who shares much of one’s background and experiences is easier and likely more accurate than empathic identification with someone of a different family background, from a different place, or of another generation. Some of the most significant tests of empathy, and some of the instances in which assumptions of commonalities are riskiest, often occur across the greatest differences

in cultures and contexts. Because of this, empathy is a vital component of theories of cosmopolitanism, which similarly struggle with the balance of universal principles and an idea of a common humanity while simultaneously recognizing that differences cannot be neglected or erased. The resulting slogan for cosmopolitanism, offered by philosopher Kwame Appiah (2006, p. 151), is “universality plus difference.” The idea of “universality plus difference” is a useful term because it demonstrates the necessary and always present tensions between the universal and the particular. These tensions are necessary because cosmopolitanism – as well as empathy – can attempt to attain validity only through the simultaneous acknowledgement of universality and of difference, two concepts that are often placed in opposition.

Empathy is of interest in anthropology both as a component of fieldwork, such as when developing an ethnography, and as an area of research itself, since conceptions of empathy vary across cultures and places. Douglas Hollan and C. Jason Throop (2011, p. 7) note the variable nature of empathy in the introduction to their collection on empathy in Pacific societies:

Like any other form of complex human behavior, empathy emerges in an intersubjective field, partially determined by the evolved, highly social characteristic of the human species, but significantly constituted and structured as well by social, cultural, linguistic, and developmental variables.

These variables point to the challenges not only in understanding different cultural conceptions and practices of empathy but of any complex behavior and encounter. An awareness and practice of empathy should attempt to account for the “social, cultural, linguistic” and other variables that might come into play when working with diverse populations. Empathy requires cultural awareness. Researchers must question their own assumptions and focus on the lives and values of the people they are working with, not only if working with members of Pacific societies, whose ways of living may be very different from their own, but also when working with members of those communities closer to home, because with greater proximity, there is greater likelihood that significant intercultural and personal differences may be overlooked. Some of this research can be conducted in preparation for a project as researchers identify the cultural contexts they will be working in and set out to learn as much as possible about those places and people. Some of the work can only be done through immersion, contact, observation, and exchange (see also ► [Chaps. 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology,”](#) and ► [26, “Ethnographic Method”](#)). Maria Lepowsky (2011) identifies empathy as a central concern in anthropology and ethnographic fieldwork, and she proposes methods that work toward a resolution, although empathy is always in process and never complete. Lepowsky (2011, p. 43) writes: “The core paradox of anthropological epistemology, method, and representation remains the human inability to experience full empathy with another person.” As a means of addressing this, she offers “ethnographically informed narrative, the process of telling and retelling stories of intersubjective experiences in the field, at home, and in print” (p. 53). Telling and retelling stories as a mutual process, shared by researchers and research participants, can move both toward a greater cultural awareness and at least a partial empathy.

3.3 Communication, Listening, and Collaboration

At the core of any practice of empathy are effective listening, communication, and collaboration. Empathy truly realizes its value when it is practiced in connection with other people and when it becomes a joint effort. A vital figure in the development of empathic listening techniques is psychologist Carl Rogers, who pioneered the client-centered approach to therapy. Much of his practice was a practice of empathy. Rogers (1961, p. 331) considered the major barrier to communication to be the “tendency to react to any emotionally meaningful statement by forming an evaluation of it from our own point of view.” Researchers, of course, should take care not to preemptively evaluate or judge a participant’s statement. The communication strategy that Rogers advances is rooted in the practice of empathy as an embodied, nonjudgmental way of listening. “Real communication occurs, and this evaluative tendency is avoided, when we listen with understanding,” he writes (p. 331). “What does that mean? It means to see the expressed idea and attitude from the other person’s point of view, to sense how it feels to him, to achieve his frame of reference in regard to the thing he is talking about” (pp. 331–332). Empathy, for Rogers, is a means of understanding not only cognitively but also emotionally by adapting oneself to another’s frame of reference. This is a powerful move both for the empathizer and the one who is empathized with. To listen with understanding, as Rogers calls it, can change the person who is empathizing. This type of listening can require courage. Rogers (1961, p. 333) advises: “If you really understand another person in this way if you are willing to enter his private world and see the way life appears to him, without any attempt to make evaluative judgments, you run the risk of being changed yourself.”

It is important to stress here that Rogers is primarily referring to occasions when people are on different sides of an argument, or in therapeutic encounters, although much of the power of empathic listening – listening with understanding – remains. Rogers offers a key technique for empathic listening, what is known as the restatement principle. In this practice, people take turns restating to one another in their own words what they heard the other person say. They can only continue with the discussion once the other’s point has been restated to the other’s satisfaction. If I were to restate what you said and you were not satisfied with how I restated it, then I would need to try again and await your approval before we could move on. This technique also was pioneered in therapeutic contexts, but the basic move remains helpful for researchers as a way of practicing empathic listening along with the suspension of judgment. It also can be helpful when practiced in the other direction, as a means of helping researchers be sure that research participants understand the project and what is happening. Listening in this way can improve empathic accuracy and help to develop a rapport among researchers and respondents as they become collaborators in understanding their exchange.

A similar orientation is proposed in rhetorician Krista Ratcliffe’s (1999) idea of “rhetorical listening.” Ratcliffe’s concept of listening is particularly useful in cross-cultural contexts. In defining rhetorical listening, Ratcliffe focuses on the significance of understanding, which for her “means more than simply listening *for* a

speaker/writer's intent" and "also means more than simply listening *for* our own self-interested intent" (emphasis original, p. 205). Instead, for Ratcliffe, "*understanding* means listening to discourse not *for* intent but *with* intent – with the intent to understand not just the claims, not just the cultural logics within with the claims function, but the rhetorical negotiations of understanding as well" (p. 205). She asks that practitioners of rhetorical listening let themselves be immersed in other discourses, in other ways of understanding, to not try to focus on only one idea or concept in order to pull it out, for the other's purposes or your own, but instead "letting discourses wash over, through, and around us and then letting them lie there to inform our politics and ethics" (p. 205). This type of listening requires an awareness of our own cultural logics and discourses as well as those of others and the ways that they all might intersect. Ratcliffe proposes this concept in the hopes that it might work at points of discursive intersection "so as to help us facilitate cross-cultural dialogues about any topic" (p. 196). Although Ratcliffe is writing with concerns of public deliberation and social discourse in mind, her approach is valid for researchers. She warns us that when we listen too closely for intent, we can miss the larger cultural discourses that surround the communication. It is important instead to listen with intent, with the intent to appreciate not only a person's words but the worldview that gives meaning to those words.

The empathic communication and listening practices put forward by Rogers and Ratcliffe underscore the collaborative nature of empathy. As stated earlier, empathy can be most effective when it is built upon a relationship. The larger context for these moves is one in which researchers are partners with their research respondents. This partnership can be realized in many ways. It involves conferring with research participants about the research project; enlisting them in helping to develop the project; making communication a cooperative enterprise that values the listening, cultural context, concerns, and understanding of all participants; and inviting them to review how they are presented in the research and how their stories might be told, considering them as coauthors, so that they too have a voice in the project (see ► [Chap. 17, "Community-Based Participatory Action Research"](#)). All of these moves help to establish research practices that are more empathic, collaborative, and ethical and thereby stronger and more effective. These are especially important when working with vulnerable population, who otherwise may not have much say in how they are considered in the project (Liamputtong 2007, 2010). For people who do not have as much power as the researchers, it is imperative that institutions and, ultimately, researchers themselves make sure that they are establishing ethical and inclusive research practices. Empathic communication, listening, and collaboration are a good start for such practices.

3.4 Self-Reflection and Critical Empathy

Because of all of the biases to which empathy is prone – and because of the tensions between self- and other-identification and the tendency to erase the other to be replaced by the self in self-focused perspective-taking – it is important that any practice of empathy be paired with self-reflection and critical empathy. These moves

help keep the liabilities of empathy in check, and they enhance empathic practices by offering mechanisms to review and revise empathy as well as recognize one's own interests and sociocultural position.

As attention to empathy has grown, popularly and within the academy, so have critiques of empathy and how it functions. As Shuman (2005, p. 18) writes, "empathy is almost always open to critique as serving the interests of the empathizer rather than the empathized." Shuman is interested in how personal stories are told and how they acquire meaning beyond the personal. Usually, the telling of these stories is in the interest of the teller rather than the person who first told the story from their experiences. This is a critique of empathy very much relevant to researchers, who risk promoting their own interests as they collect and tell the stories of others. As Shuman adds, empathy "rarely changes the circumstances of those who suffer" (p. 5). And so she puts forth a critique of empathy that "avoids an unchallenged shift in the ownership of experience and interpretation to whoever happens to be telling the story and instead insists on obligations between tellers, listeners, and the stories they borrow" (p. 5). Literary scholar Theresa Kulbaga (2008) similarly critiques empathy, in this case the easy empathy of some cross-cultural novels, for merely catering to the pleasures of the readers, because empathizing with distant others in ways that are comfortable can be fun. Western readers are allowed to enjoy the empathic reading experience and "remain in the realm of individual imagination, where affect remains divorced from either critical reflection or political action" (p. 517). She recommends instead that we ask "empathy to what end?" (p. 518). By questioning the conveniences of empathy, by realizing how empathy can be inviting or complacent, by acknowledging the commitments of empathy, and by asking what empathy does in a given situation, we can take a more critical approach to empathy, one that does not see empathy itself as an end but as a means toward a larger project. Researchers do well to ask themselves how they are involved in the empathic situation, how the interests of everybody are being served, what commitments for change and continuing relationships the situation proposes, and what the effects of empathy in that situation are.

The practice of critical empathy requires recognition that empathy is always an approximation and is always incomplete. By reflecting upon our own empathic processes, we can better realize the limitations of empathy and not make unacknowledged assumptions. Education professor Todd DeStigter (1999) advocates the practice of critical empathy as a way of forming relationships in communities across differences even while recognizing the limitations of empathy and how those relationships can be uneven. DeStigter (1999, p. 240) defines critical empathy, which he adopts from Jay Robinson, as:

the process of establishing informed and affective connections with other human beings, of thinking and feeling with them at some emotionally, intellectually, and socially significant level, while always remembering that such connections are complicated by sociohistorical forces that hinder the equitable, just relationships that we presumably seek.

For DeStigter, the position of the researcher is part of the complication, because it is unequal to that of the other and is subject to sociohistorical forces. Still, those

limitations do not mean that we should give up on empathic connections. Instead, they require that we be aware of the limitations and try to work with and within them. For researchers, then, the trick is not to act as though all participants, researcher included, are on equal footing but to acknowledge disparities and invite connections and collaborations across differences, making the differences themselves open to reference, critique, and, hopefully, some counterbalance as participants find points of commonality and connection.

4 Limitations and Risks of Empathy

The most significant limitations of empathy are biases. Simply put, we tend to empathize most readily with those most like ourselves. Hoffman (2000, p. 197) calls this the “familiarity bias.” The greater the differences between myself and somebody else, the greater the challenge to empathize. As a corollary, if there are two people with whom I might empathize, I likely will empathize more easily and effectively with the person most like me. We see empathic failures due to familiarity biases all of the time in our public discourse, as people empathize with the victims most like themselves and downplay or ignore the claims of others. As above, researchers would do well to question their empathic impulses and to reflect upon the processes of empathy, including their own subjectivities and positions, that might lead them to more readily empathize with one person over another.

A second bias to which empathy is prone is the bias of immediacy, what Hoffman (2000, p. 197) calls the “here-and-now bias.” We are more likely to empathize with somebody when that person is in our immediate vicinity, when we are witness to that person’s emotions, rather than to empathize with somebody more distant. This bias is due in part to empathy’s reliance upon automatic and nonverbal modes, such as body, facial, and affective cues, that are relayed through face-to-face interactions. Bloom’s (2016) argument against empathy as a moral guide is based largely upon this bias. It can affect researchers in many ways, perhaps most significantly in the choice of research topics and sites of research. We are liable to investigate issues that affect those nearest us without proper consideration of what might be a more beneficial use of our time in researching issues that affect more distant populations more significantly. When weighing the ethics of research, as informed by empathy, it is important to consider not only our interactions with others in the course of research but also how we come to be interested in and to choose our research topics and sites.

An additional risk of empathy is the way that it can be self-serving and can disadvantage people with whom we are working. Because empathy generally is considered an unopposed positive value in Western societies, it is easy to use empathy as a justification for work that might serve our interests more than those of the people we are working with. So long as we are empathizing, we might unreflectingly give ourselves a pass and not question deeper motivations for and consequences of the work. The critical empathy practices addressed earlier are intended to help mitigate this. Empathy tends to flow down social power gradients.

By that I mean the more powerful tend to be in a better position to empathize with the less powerful; empathy is directed up less frequently. These differences in power can have adverse effects on the people who are empathized with, as they leave the empathic encounter reminded of their lack of social standing and power and less motivated to pursue their goals (Vorauer and Quesnel 2016; Vorauer et al. 2016). Again, the practice of a critical empathy and the development of long-term collaborations, in which participants are treated as co-creators with a voice in the research projects, hopefully can help counteract these negative outcomes. It also is worth noting that disparities in social power and standing precede empathic encounters. When practiced effectively, processes of empathy may help shine a light on some of these issues in ways that help them be addressed rather than ignoring disparities that nevertheless could still have negative implications for the work.

5 Conclusion and Future Directions

As should be clear, empathy is not a research method in itself but works as a component of multiple methods. It may be considered and practiced as a methodological framework. Part of the value of empathy is in its incorporation of the cognitive and the affective, its recognition that we think not only with the logical parts of our minds but also emotionally and with the whole body, extending even into our interactions with others and with our environments. As a component of research processes, empathy can lead to new insights and commitments and more meaningful ways of communicating. Many people are initially drawn to ideas of empathy because it seems so unquestionably positive, but empathy is not an unalloyed good. It can empower biases and lead to erroneous conclusions and problematic actions, all under the cover of positive empathy. Hence, we need practices of critical empathy.

Increased public interest in empathy speaks to the times in which we live. It seems not merely a coincidence that interest in empathy has grown at the same time that we face greater social divisions, widespread inequalities, and the challenges of engaging others near and far across more significant differences. Empathy suggests a means for how we might navigate those processes of communication, cooperation, and mutual understanding in our many interactions. Although far from perfect, empathy does offer hope that we can learn to respect and work across our differences. As we learn more and further develop our concepts and practices of empathy, our work and our relationships stand to benefit.

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Indigenist and Decolonizing Research Methodology

15

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Contents

1	Introduction: What Is an Indigenist Research Paradigm?	254
2	Some History	255
3	Institutional Racism and Health: Ongoing Colonization	256
4	Survival and Resilience	257
5	Why Indigenist and Decolonizing Research in the Health Social Sciences	258
6	Indigenous Knowledge as a Protective Factor	260
7	Non-indigenous Researchers Using Indigenist Methods	261
7.1	Critical Self-Reflexivity	262
7.2	Supporting Indigenist and Decolonizing Methods	263
8	Conclusion and Future Directions	264
	References	265

Abstract

European colonization of Indigenous nations has severely impacted the health of Indigenous peoples across the globe. Much of the burden of ill health suffered by Indigenous people today can be traced directly back to colonization. Indigenous peoples of all first world nations where colonization has occurred are experiencing epidemic proportions of chronic disease, higher levels of morbidity and mortality, and poorer health outcomes compared to non-Indigenous populations. Indigenist and decolonizing approaches to research with Indigenous peoples have emerged in recent years with the overall aim of recognition and inclusion of Indigenous epistemologies and ontologies within the western research paradigm. A significant barrier to achieving this is the disconnection between the dominant

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biomedical approach to health and the holistic understandings of health based on Indigenist philosophies and traditional healing practices and knowledges. Conducting research that can successfully inform and improve health services and outcomes for Indigenous peoples requires a decolonizing approach where the voices of Indigenous Elders and communities are the primary informants. Integrating Indigenous ways of knowing, being, and doing with western biomedical approaches requires respect for and inclusion of Indigenous Knowledge as healing methods that have preserved community and individual well-being for thousands of years.

Keywords

Indigenous Knowledge · Colonization · Trauma aware practice · Healing culture · Dominant western paradigms

1 Introduction: What Is an Indigenist Research Paradigm?

Indigenist research respects and honors Indigenous ways of knowing, being, and doing through using methods that are informed by, resonate with, and are driven and supported by Indigenous peoples. Researchers working respectively with, and learning from Indigenous peoples aim to decolonize western research methodologies and methods in order to include Indigenous ways of seeking, analyzing, and disseminating new knowledge. In order to apply an Indigenist research paradigm to the health services sector, researchers from non-Indigenous backgrounds must firstly examine their own worldview(s) to enable them to understand that their view of the world is different than that of the Indigenous peoples with whom they are working. Indigenist research is characterized by approaches grounded in relationality and the inclusion of Indigenous ways of communicating such as storytelling or “yarning” as it is referred to in Australia (Bessarab and Ng’andu 2010; Rix et al. 2014; Wilson 2008). Applying Indigenist ways of conducting research is in accord with the United Nations Declaration on the Rights of Indigenous Peoples which states that:

Indigenous peoples have the right to maintain and strengthen their distinct political, legal, economic, social and cultural institutions, while retaining their right to participate fully, if they so choose, in the political, economic, social and cultural life of the State. (United Nations 2008, Article 5, p. 5)

Indigenist research has been a growing body of new knowledge production over the past two decades, led by Indigenous scholars from Canada, Australia, and New Zealand. Indigenous scholar and Maori woman Linda Tuwahi Smith’s groundbreaking book *Decolonizing Methodologies: Research and Indigenous Peoples* (Smith 1999) articulated Indigenous research methodologies that ensure Indigenous intellectual sovereignty of projects involving Indigenous people, interests, and concerns. A number of international scholars have built on the body of knowledge about Indigenist research methodologies. The work of Indigenous scholars in the

Americas, Africa, and Australasia has illuminated the core principles of an Indigenist paradigm for conducting respectful and safe ways for Indigenous peoples to conduct research with both their own people and other Indigenous communities. From an Indigenous methodological perspective, the entire research process must be redefined and reframed (Rigney 1997; Weber-Pillwax 2001; Martin 2008; Wilson 2008; Kovach 2010; Chilisa 2012; Kite and Davy 2015).

While Indigenous scholars from first, second, and third world nations do share methodological commonalities, researchers must be mindful not to categorize these as a homogenous group, and outsiders have no right to do so. One thing that we do share is our colonized histories and the contemporary impacts on the social, health, and political positioning of Indigenous peoples living under western governance. We are also connected via our evolving Indigenous methodologies (Walter and Anderson 2013). The collective work of these groundbreaking Indigenous scholars has built an international body of work that is now making inroads into western academic methodologies and protocols (see also ► Chaps. 87, “Kaupapa Māori Health Research,” ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research,” ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,” and ► 97, “Indigenous Statistics”).

2 Some History

Everything on Earth has a purpose, every disease a herb to cure it, and every person a mission. This is the Indian Theory of Existence. (Morning Dove, Salish)

Indigenous peoples colonized by Europeans share a history of dispossession, trauma and loss of culture. The United States, Canada, Aotearoa/New Zealand, and Australia, for example, are all developed nations with common experiences of European colonization. For Indigenous peoples in these wealthier nations, seizure of land and extermination of whole communities or tribal groups were universally common and carry ongoing repercussions (Stephens et al. 2006). While the non-Indigenous populations of these countries generally enjoy high standards of living and health, Indigenous populations experience significantly poorer socio-demographic and health outcomes (Anderson and Whyte 2008). Indigenous peoples also share significantly lower life expectancy, with “epidemic” levels of chronic conditions such as cardiovascular disease, diabetes, and renal failure (King 2010; Centres for Disease Control and Prevention 2014; Australian Institute of Health and Welfare 2015).

Since the initial shock of invasion by Europeans, Indigenous peoples have been forced to give up language culture and understandings through generational impositions that separated individuals, families, and whole nations from their original knowledge systems and social structures. These traumatic events have disintegrated family and community relationships, structures, and traditional lifestyles. The profound impacts of colonization have been further compounded by the enduring history of successive failed government policies and practices (Durie 2004;

King et al. 2009). For example, the removal of Indigenous children from their families and their detention in government-controlled and Christian church-run residential schools were reinforced through government policy in both Canada and Australia throughout the nineteenth and twentieth centuries. Similar negative and traumatizing experiences when engaging with all government services further connect Indigenous peoples from the United States, Canada, Aotearoa/New Zealand, and Australia (Walter and Anderson 2013).

In her 1998 book, *Colonizing bodies*, the author Kelm explored how Canadian Indigenous peoples were not only materially affected by the colonizer's Canadian Indian policies; restricting hunting and fishing and the forced removal of children into unhealthy residential schools, traditional healing, and cultural practices were criminalized. The author discusses the impact of the use of humanitarianism and western medicine to pathologize Aboriginal bodies and inflict a monoculture of biomedical approaches in the name of assimilation (Kelm 1998). The removal of entire communities from their lands into missions and reserves was common practice, with the use of missionaries and Christian doctrine to further demonize and eliminate entire family and cultural frameworks (Kelm 1998).

Indigenous peoples in Australia and the United States experienced similar treatment under colonial policies aiming to assimilate Aboriginal peoples and destroy cultural and family structures using extreme inhumane measures, including removal of children from their families and communities.

The deliberate state-led destruction of Aboriginal communities, languages, and cultural practices has inflicted profoundly damaging levels of trauma. The systematic removal of Indigenous Australian children from their families and communities, creating the Stolen Generations, has deeply impacted social and emotional well-being, with these impacts being passed on via trans-generational trauma (Atkinson 2002). This trauma is an antecedent to Indigenous Australian peoples now suffering a huge gap in health and well-being when compared to non-Aboriginal Australian populations. Emerging theories generated by the study of epigenetics have now linked damaging environmental factors in utero and during early life and begin to explain the causation of the current epidemic of chronic disease and early mortality (Hoy and Nicol 2010). The disconnection of generations of Indigenous children from their land, families, and communities created a direct causal pathway to the current epidemic proportions of chronic disease across all first world colonized nations. Indigenous scholars stress the impact of "cultural detachment" which includes separation from people and country, loss of traditional diet, lifestyles, language, and stories on their people, evidenced in the spiralling incidence of diabetes and other chronic conditions in Indigenous populations (Sanderson et al. 2012).

3 Institutional Racism and Health: Ongoing Colonization

While we could delve further into the ongoing impact of historical trauma, it is important to recognize the ongoing nature of colonial experiences for Indigenous people. Experiencing racism is now known to have a direct physiological impact on

health and well-being. Recent work has reviewed the scientific research on how racism adversely affects the health of non-dominant cultural groups. Multiple causal pathways have been identified by which racism can affect health, with institutional and cultural forms of racism being major contributors to health inequalities (Williams and Mohammed 2013). Concepts such as black inferiority and white superiority have been historically embedded in American culture and continue to impact American First Nations people today.

The link between poor health and racism for Aboriginal people was explored in depth by Australian Indigenous scholar Yin Paradies in his doctoral thesis entitled “Race, racism, stress and Indigenous health” (Paradies 2006). This epidemiological study showed strong and persistent associations between chronic stress resulting from experiences of racism and poor physical and mental health, including depression, and increased risk factors for heart disease and other chronic health conditions.

Racism is inherent within colonial government organizations and is beginning to spawn its own research. Reluctance to engage with western biomedical health services by Indigenous peoples is underpinned by a complex blend of historical, political, and economic drivers. Mainstream health services continue to lack acknowledgment and understanding of the historical trauma and racism that are the antecedents to Indigenous people’s avoidance of and lack of confidence in mainstream biomedically driven health services (Larson et al. 2007). Originating at colonization and reinforced by ongoing experiences of overt individual and institutionalized racism, Indigenous people and communities remain highly suspicious of engaging with government services. In the health services context, there remains a culture of blaming and judgment of Indigenous people suffering chronic illness, despite the rapidly increasing incidence of similar patterns of “lifestyle-induced” chronic conditions in all non-Indigenous populations of first world nations (Rix et al. 2014).

Despite contemporary research showing inclusion of cultural and traditional healing methods as the way forward in addressing the serious health disparities suffered by Indigenous people, this is not translating into practice (Poche Indigenous Health Network 2016). Indigenous peoples’ fear and avoidance of western healthcare systems coupled with the “one-size-fits” approach of the biomedical model remain major institutional barriers. In view of this history, it is vital that any research performed with the aim of improving health services acknowledges this by incorporating and utilizing Indigenous ways of creating new knowledge. Dissemination of findings and recommendations requires researchers to collaborate with community to ensure methods are negotiated with and approved by Indigenous Elders and community.

4 Survival and Resilience

Survival and resilience are fundamental qualities that unify colonized Indigenous peoples (Tousignant and Sioui 2009; Ramirez and Hammack 2014). Despite the deficit-based approach to “problematizing” Indigenous peoples and their health, a

universal strength of all colonized Indigenous peoples is their remarkable survival and resilience, even in the face of the relentless attacks by dominant western governments, aiming to annihilate Indigenous cultural traditions and silence Indigenous voices. This shared history of extreme violence, trauma, and dispossession has, however, highlighted Indigenous peoples' abundant resilience and strengths. Indigenous peoples' ability to survive and heal from a succession of damaging and hegemonic government policies unites them (Fast and Collin-Vezina 2010).

Cultures of resistance emerge within these dominated populations fostering forms of non-compliance and aberrant behaviors that protect individuals and communities and ease the burdens of dominance. These weapons of the weak often divert and delay actions instigated by the dominant and conceal resistance because they are interpreted to be evidence of the lesser ability of the dominated. The essential tactic of avoidance is a part of resilience and also a key factor in externally applied research because approaches such as surveys may not truly reflect the Indigenous population (see also ► Chap. 97, "Indigenous Statistics"). In this way Indigenous populations routinely subvert research, avoid treatment, and ignore initiatives (Sheehan et al. 2009).

There is an urgent need to transform western government and policy dialogues about Indigenous peoples' health and well-being from a negative, deficit-based focus. We do not need more research that tells us how well colonialism is still working (Walter and Anderson 2013). Indigenous leaders and culturally competent and skilled healthcare professionals are stipulating a strength-and right-based approach to health policy and practice for Indigenous people (Tsey et al. 2007; Jackson et al. 2013; Neumayer 2013). Elders and Indigenous communities have been calling for Indigenous Knowledge and healing methods that have sustained Indigenous societies for thousands of years to be incorporated with western medical practices (Moodley 2005; Shahid et al. 2010).

5 Why Indigenist and Decolonizing Research in the Health Social Sciences

Indigenous Peoples must look to new anti-colonial epistemologies and methodologies to construct, re-discover and/or re-affirm their knowledges and cultures. Such epistemologies . . . strengthen the struggle for emancipation and liberation from oppression. (Rigney 1997, p. 115)

Indigenous peoples have suffered a long history of having been "researched on" by western anthropologists and academics from other disciplines. As a result, many are cynical about the benefits of participating in western academic research, being wary of the colonial lens, and assumed superiority of western researchers (Prior 2006). Australian Indigenous peoples, for example, have witnessed some two centuries of being "over researched" with no prior consultation, permissions sought or any form of post research feedback or positive outcomes. There is a common recognition among many Indigenous peoples that western research paradigms contributed to their ongoing oppression. Research that is framed and supported by the

very system that has dispossessed and oppressed Indigenous people has an inherent bias toward maintaining that system. Aboriginal communities in Australia have long held practices that subtly disable intrusive research (Sheehan et al. 2009).

Given this history and the urgent need to address the immense health disparities suffered by Indigenous peoples in colonized first world nations, there is an urgent need to conduct research differently. We cannot expect the same system of thinking that has caused such large health disparities to be able to envision a solution. Research must, therefore, be conducted in a way that fully captures and honors the voices and perspectives of Indigenous peoples but, more importantly, emanates from an Indigenous ontological and epistemological basis. This is Indigenist research. It ensures that Indigenous Knowledges, experience, and wisdom are captured, applied, and disseminated in ways that resonate with Indigenous ways of knowing, being, and doing. Sherwood (2010), Australian Indigenous nurse and scholar, has applied this approach to decolonizing Indigenous health services and research in her doctoral thesis “Do no harm: Decolonising Aboriginal health research.” Sherwood argues that any research aimed at decolonization of Indigenous healthcare must be initiated and guided by Elders and underpinned by Indigenous critical theory and the balancing of two ways of knowing. This approach leaves no room for the “problematizing” of Aboriginal people in the healthcare context, which results in the silencing of Indigenous voices, subjugation of Indigenous Knowledges, and Indigenous peoples being viewed as the “Other” (Sherwood 2010).

All research is appropriation, and, therefore, it should be conducted in a way that ensures that both the researched and the researcher benefit (Chilisa 2012). Normalized positions of dominance must be recognized and deconstructed and deficit discourses replaced with respectful representation that leads to opportunities for sharing, growth, and learning. This approach restores hope and belief in a community’s capacity to resolve challenges (Chilisa 2012). Elders and community members are indeed the experts in the health and well-being of their own people, with knowledge and expertise reaching back thousands of years prior to the evolution of the biomedical model of health and the colonization of their nations by Europeans.

Indigenist researchers have developed theoretical frameworks and research methods that are congruent with Indigenous belief systems that have been known for millennia. As the substantive theory underlying Indigenist research continues to be further articulated, Indigenous truths that are informed by Indigenist methodologies have emerged. These truths are based on our own ontological and epistemological foundations and, therefore, have the ability to envision solutions to seemingly intractable health problems. A common feature among many Indigenous peoples’ ontology is that we are relational. That is to say, we do not engage in relationships, nor are we in relationships, but we are relationships. Our very being, and the nature of reality itself, is relational. We are relationships with people and communities, with the Land, with ideas, with everything. Indeed, nothing would be (or exist) without relations (Wilson 2008). Aboriginal scholar Mary Graham builds on this relational ontology with her statement “You are not alone in the world.” Here Professor Graham describes the survival of a contemporary Indigenous kinship

system based on relationality, despite the damage inflicted by the colonizer's urbanization of Aboriginal people using (attempted) cultural genocide. The central role of Indigenous people's connection and relationship to land is clear in her writing:

Although Indigenous people everywhere are westernised to different degrees, Aboriginal people's identity is essentially always embedded in land and defined by their relationships to it and to other people. The sacred web of connections includes not only kinship relations and relations to the land, but also relations to nature and all living things. (Graham 2008, p. 187)

Fundamental to Indigenist research is an understanding that the researcher is not outside of reality looking in but has entered into a different set of relationships with the people and issues that they are researching. So, among the truths that emerge from an understanding of relationality is that researchers, as knowledge producers in relation, are in themselves accountable for maintaining healthy relationships with the communities, environment, and ideas that they are researching (Wilson 2008).

Reflexive practice is essential for any researcher in examining their motivations and intent in working with Indigenous people. Just as Indigenous scholars apply a critical lens to their work with their own people or other Indigenous communities, examining why and how they are doing research, close scrutiny is vital:

If my work as an Indigenous scholar does not lead to action, it is useless to me or anyone. I cannot be involved in research and scholarly discourse unless I know that such work will lead to some change out there in that community, in my community. (Weber-Pillwax 2001)

Indigenist methodologies view the rigor and validity of research as determined through relational accountability (Wilson 2001). Researchers have relational accountability to participants, co-investigators, and the overall conduct of the study. For the non-Indigenous researcher, relational accountability is encapsulated by principles of respect, responsibility, and reciprocity (National Health and Medical Research Council 2003; Rix et al. 2014). The long-term destiny or agency of research findings can work against or in favor of the researched, and this reinforces the responsibility of the researcher (Glowszewski et al. 2012). The principles of reciprocity underpin Indigenous cultural and social identity. They relate to Indigenous rights and obligations of sharing within community (Schwab 1995). As reciprocity implies collaboration, choice, and respect, it must be deeply embedded within the research methodology and methods. Consideration must be given to where money is spent in community, what protocols are acknowledged, and how the researcher is giving back to those being researched. Opportunities to co-author research, leave knowledge, learnings and skills within the community, and respecting protocols all constitute reciprocity (Ellis 2016).

6 Indigenous Knowledge as a Protective Factor

Once we understand the relational nature of reality, we can see that Indigenous cultures are built upon complex systems of relationships and relational accountability. Therefore, Indigenous culture itself is a pathway to healthy relations and healing

for Indigenous people (McDonald 2006; Aboriginal and Torres Strait Islander Healing Foundation 2014). When combined with western medicine, Indigenous Knowledge and cultural healing can provide ways for people to gain control over their lives.

Mainstream initiatives that engage with Aboriginal cultural practice, philosophy, spirituality and traditional Aboriginal medicines are examples of how to enact the theoretical concept of Indigenous Knowledges into reality and practice. However, there are too few examples of where this is happening in a meaningful and enduring way. (Poche Indigenous Health Network 2016)

Healing for Indigenous people takes place by way of reconnection to country, family, and culture (Maher 1999; Watson 2001; Kirmayer et al. 2003). Cultural healing may be from reconnecting to Indigenous ways of knowing, being, and doing, art, dance, or simply sitting down with Elders and listening to the traditional stories passed down through the generations (Hunter et al. 2006; Aboriginal and Torres Strait Islander Healing Foundation 2013).

Any superficial acknowledgment of culture must be accompanied by a fundamental acceptance of Indigenous ontology and epistemology at the foundational level of research planning. It is not enough to window dress western practices with cultural artifacts; the issue of power imbalance of the two knowledge systems needs to be addressed. This entails collaboration, trust, and the ability to push back against our conditioned belief that the western biomedical way is the only right way. It cannot be simply acknowledging that we have two proven knowledge systems; there must be systemic change. To change the system, we must be able to understand both knowledges, value them equally, and implement what is important. It is about allowing the historically oppressed to find their voice and power and sit with equality at the table when decisions are being made. If we want true equality and healing, one side must be willing to give up the power of control.

Indigenous culture has never been static. Indigenous communities have always placed the well-being of their people and their lands at the center of their governance and have been able to evolve and embrace change with resilience. Culture is not just dance, ceremony, and language; it is a philosophy and worldview that is based on collective ways of knowing and being. Collective community is the relationship to all things from the wind and weather to the waters, lands, and its peoples. To pay lip service to culture by engaging artifacts results in a hollow attempt to show cultural safety. True healing will happen when culture is not filtered through the western ways of knowing. It is when Indigenous peoples can make decisions for the services that govern them.

7 Non-indigenous Researchers Using Indigenist Methods

Working with Indigenous peoples in a research capacity requires the non-Indigenous researcher to bracket their own worldviews and apply a critical reflexive lens to any project they contribute to (Rix et al. 2014). Reflexivity can be an effective instrument

for mitigating power, class, and cultural differences in research (Bott 2010). When working with Indigenous peoples and communities, with the aim of improving health services delivery, it is crucial to proceed respectfully and remain ever vigilant of applying an epistemological approach which privileges Indigenous voices. Self-determination, addressing power imbalances, and community control must remain central to any research project performed by outsiders and non-Indigenous researchers with Indigenous communities (Rigney 1997).

According to Wilson (2007), working within an Indigenist paradigm is not limited to Indigenous researchers, just as working with a western paradigm is not restricted to researchers of “white” descent, or working with a “feminist” methodological approach is not restricted to being female. Non-Indigenous researchers are accountable to Indigenous community and elders, and it is essential that they develop mutual trusting relationships. Taking responsibility for the cultural safety of Indigenous research participants via deep consultation with elders and community to confirm that any proposed research is in accord with the needs and desires of that community is essential in the commencement of any research project.

Notions of white privilege and white guilt have emerged over roughly the same time frame as the Indigenist paradigm has been evolving. In her pivotal work, Peggy Macintosh, an American feminist and antiracism activist, described the “invisible knapsack” containing all the privileges that being a member of white middle-class society delivers (McIntosh 1990). White guilt is a concept that is defined as the individual or collective guilt felt by some white people for harm resulting from racist treatment of ethnic minorities by other white people both historically and currently (Steele 1990).

Both these concepts may form part of the non-Indigenous researcher’s personal process of unpacking their own worldviews using critical reflexive practice. They are, however, of no value in the role of the non-Indigenous researcher seeking to advocate for and find creative ways to contribute to the honoring and inclusion of Indigenous Knowledges into mainstream health services research. Of more importance here is the non-Indigenous researcher’s ability to develop open listening skills and bracket their own worldviews in order to view the world through the lens of the Indigenous peoples with whom they are working.

7.1 Critical Self-Reflexivity

It is of vital importance that before any first meeting or consultation with Indigenous community takes place, the non-Indigenous researcher must undertake a personal journey of critical reflexive practice in order to examine and comprehend their own position as a white person of privilege (McIntosh 1990). This process extends beyond mere awareness of colonizing histories and power imbalances, to examining one’s own worldviews and the biases and assumptions that come with being a member and product of the dominant western culture. Without a genuine and ongoing process of critical examination of self, reflecting on the privileged lens through which the world is viewed, the non-Indigenous health services researcher is

at risk of merely contributing to and continuing the colonization process, further embedding the dominant western paradigm that cannot provide either re-empowerment or self-determination (see also ► Chaps. 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research,” ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze” and ► 98, “A Culturally Competent Approach to Suicide Research with Aboriginal and Torres Strait Islander Peoples”).

Practicing critical reflexive practice requires a toolkit. This may include, for example, regular journaling and development of strong relationships with Indigenous people as research colleagues and co-investigators. Examining one’s influence on and positioning within any research performed with Indigenous communities is a crucial ingredient of preparation to work with Indigenous peoples using a relational and Indigenist methodology. It is important, however, to be aware that positioning and clarification of roles in any research endeavor are of far less importance than the non-Indigenous researcher’s effectiveness as a research “instrument” who can contribute to improvements to health services in ways that resonate with and reflect the Indigenous peoples with whom they are working (Rix et al. 2014). To be successful in informing policy and positive change requires researchers to manage complex relationships between Indigenous individuals, communities and organizations, and the dominant biomedical world they are required to negotiate to access healthcare and treatment.

7.2 Supporting Indigenist and Decolonizing Methods

There are a number of important strategies that non-Indigenous researchers can use as advocates for and practitioners of Indigenist and decolonizing methodologies:

- Citing the co-creation of new knowledge as a relational exercise that cannot occur in isolation. An individual cannot own new knowledge.
- Not trying to know or understand too quickly because relational approaches with Indigenous peoples operate to an inside learning timetable; true change is paced to things other than research programs or publishing deadlines (Gnibi Elders Council 2016; Murphy 2017).
- Use of Indigenous ways of disseminating research findings, for example, storytelling, artwork, and use of metaphors.
- Publishing in health and medical journals with Indigenous Elders, community members, or research participants as co-authors.
- Publishing research results in the voice of the Indigenous participants.
- Illustrating research output such as new theory and data analysis using Indigenous artwork.
- Introducing co-authors and a little of their stories or background in publications, to enable the reader to build their own relationship with authors.

This list while by no means comprehensive provides examples of ways that non-Indigenous researchers can contribute to the use and acceptance of Indigenist

methods. Academic processes often act to block or negate the influence of paradigms that challenge the dominance of western and biomedical worldviews. The inclusion of Indigenous research methods that resonate with individual participants, Indigenous Elders, and community members are becoming more commonly used and accepted within western academic conventions.

8 Conclusion and Future Directions

The purpose of this chapter is to familiarize health social scientists with the rapidly growing prominence of Indigenist and decolonizing methodologies, providing an emphasis on how these can make important and significant contributions to the health services research arena. In fact, we strongly argue that without the inclusion of Indigenous ways of knowing, being, and doing and the voices of Elders, community members, and individual Indigenous participants, there can be little or no improvement to provision of effective health services or improved health outcomes for Indigenous peoples.

The profoundly damaging impact of European colonization on Indigenous nations is the known primary driver of the current burden of ill health suffered by Indigenous peoples across many countries. Performing research with Indigenous peoples using epistemological and ontological approaches that incorporate Indigenist philosophies and traditional knowledge and practices is now known to be a genuinely decolonizing approach to research aimed at improving health and well-being.

Researchers aiming to work with Indigenist methodologies are required to use ongoing critical self-reflection to both unpack their own existing worldviews and acknowledge their privilege. Awareness of and insight into the relational and interconnected worldviews and philosophies of Indigenous peoples are vital for anyone wishing to work in this area. Any project must be approached with “respect, responsibility, and reciprocity” as the foundational principles of ethical research performed with Indigenous communities and individuals. It is also vital that researchers be mindful of the underpinning driver of Indigenist methodologies and methods: to increase the empowerment and self-determination of the Indigenous population under investigation.

In writing this chapter, we sincerely hope that more non-Indigenous researchers will be motivated and inspired to incorporate Indigenist methods and ways of knowing being and doing into any research project aiming to improve health services design and delivery for Indigenous populations. Until the western and biomedical dominance of research is broken, it is difficult to envisage how mainstream health services can successfully address the current and ongoing epidemic of chronic disease suffered by Indigenous peoples and reduce the disparities in morbidity and mortality between Indigenous and non-Indigenous populations in colonized nations across the globe.

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Ethnomethodology

16

Rona Pillay

Contents

1	Introduction	270
2	Background of Ethnomethodology	271
2.1	The Ethnomethodological Perspective	271
2.2	Emergence of Ethnomethodology	272
2.3	Ethnomethodology: Core Concepts	273
2.4	Member Categorization and Conversational Analysis as the Two Sacksian Notions	275
3	How Ethnomethodology Is Done	276
3.1	Ethnomethodology and Common Sense Procedures	276
3.2	Breaching	277
4	Data Collection Techniques: Gathering Information	277
5	Ethnomethodology: Compatibility and Use with Other Methodologies	278
6	Ethnomethodology: Weaknesses and Limitation	278
7	Ethnomethodology: Strengths and Advantages	279
8	Practicalities of Using the Methodology	279
9	Ethnomethodology in Action	280
10	Conclusion and Future Directions	281
	References	281

Abstract

Ethnomethodology is a qualitative research methodology which has recently gained momentum across disciplines, more specifically social and health sciences. Ethnomethodology focuses on the study of methods that individuals use in “doing” social life to produce mutually recognizable interactions within a situated context, producing orderliness. It explores how members’ actual, ordinary activities produce and manage settings of organized everyday situations. Practice

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through everyday life is central to ethnomethodology, the methods of which produce and maintain accountable circumstances of their life activities, making use of common sense knowledge in mundane situations. Ethnomethodology originated from Garfinkel who criticized Parsons' action theory whereby Garfinkel illustrated how ethnomethodology departs from conventional social theory to develop a methodology for studying social life. Ethnomethodology draws on video-recorded data as a preferred method with detailed attention to talk-in-interaction and gestures as interaction. The rich, detailed data generated may be viewed several times over, thus demonstrating that the data is valuable and trustworthy. The concepts of indexicality, reflexivity, and accountability are central to ethnomethodology because together they illustrate meaning as a methodical accomplishment. The reflexive accountability that contributes to order and the members' local performance of shared methods to carry out a joint activity form the central values of ethnomethodology. The analytical resources of ethnomethodology have been used to produce procedural accounts of human conduct in zones like museums, classrooms, and sports. Hence health care can be explored and empirically investigated as local interactions to contribute to patient safety.

Keywords

Ethnomethodology · Indexicality · Reflexivity · Accountability · Practice and orderliness

1 Introduction

Activities and interactions in society occur through members engaging and taking part in practical activities, mostly in everyday life activities. It is here that member's interact and arranges everyday affairs in different settings like the sports field, homes, workplace, train stations, and museums. In the sociology of everyday life, be it personal or professional, events are looked at in the "real world" and how activities are organized in the everyday life, notably, the workplace for the purposes of this chapter. According to Garfinkel (2002), the primary role of ethnomethodology is to examine the social facts of the real lived case asking, what makes it accountably just – the whatness of that social fact. Ethnomethodology primarily considers the problem of order by combining a "phenomenological sensibility," as stated by Maynard and Clayman (1991), with the focus on everyday social practice. Holstein and Gubrium (2005) agree that ethnomethodology sees the social world being accomplished by how the members constitute interactional work, the activities of which produce and maintain the accountable circumstances of their lives. Health team interactions fall within the category of social interactions; hence ethnomethodology is gradually being introduced in health research. Ethnomethodology is relatively new, making a presence in just the last few decades in the world of social sciences and even more so in health research. While used effectively in other areas like museums, courtrooms, and sports, ethnomethodology in health care is a fairly recent phenomenon in health research. Therefore, this chapter calls for the

introduction of readers to the use of ethnomethodology in health care to contribute to the advancement of team interaction and patient care and safety. The chapter provides assistance with its use in fieldwork, epistemological, ethical, and practical considerations for researchers. This chapter overviews ethnomethodology and a discussion of its actual research practices. The key aims of the chapter are to provide an outline of the emergence of ethnomethodology and offer a theoretical perspective and methods of ethnomethodological research. In addition, included in this chapter are strengths, advantages, weaknesses, and limitations, a brief mention of compatibility as used with other methods. A discussion of key issues and practicalities of using the method and an illustration of some examples of the use of and ways of doing ethnomethodology and advocating areas where this method could be used within health social sciences will conclude this chapter.

2 Background of Ethnomethodology

Ethnomethodology is a unique qualitative social science research methodology, known to differentiate itself from traditional presuppositions and purpose, more so in its treatment of methods and methodology. It is unique in that instead of prescribing specific research methods, it studies methods in use and suggests a collectivity's methodology as a fundamental topic (ten Have 2004). Ethnomethodologist's investigations tend to be more "empirical" than is usually the case for philosophical and humanistic scholars. They conduct case studies involving actions in selected social settings. In the study, careful attention is given to detail to describe or explain observable or at least reconstructible events. In addition, of particular importance, is that ethnomethodological studies focus on local situations of language use and practical interactions (Lynch 1999).

According to Lynch (1993), ethnomethodology and the sociology of scientific knowledge are usually considered to be subfields of sociology. Ethnomethodology is more often said to be the study of "micro"-social phenomena such as the range of "small" face-to-face interaction occurring in public places, sports fields, and workplaces and is used across disciplines. Lynch (1993) proposes that ethnomethodology be used not because of the society it investigates but due to its epistemic focus. While ethnomethodology "does not imply a unifying theory and method" (Lynch 1999, p. 220), it does hold a set of propositions that informs the practice of ethnomethodological studies. The next section delivers the emergence of ethnomethodology.

2.1 The Ethnomethodological Perspective

In this section, the birth of ethnomethodology will be detailed, together with progression of ethnomethodology. For Garfinkel (1967, p. 1) the studies of ethnomethodology look into "practical activities, practical circumstances, and practical sociological reasoning as topics of empirical study." Ethnomethodology is specific in explicating the ways, in which a group of members create and maintain a "sense of

social structure” (ten Have 2004, p. 16), which is an intelligibility and accountable local social order (Garfinkel 1967; ten Have 2004). Specific attention is paid to common place activities of everyday life and seeks to learn about these as a phenomenon in its own right. Garfinkel (1967) envisioned ethnomethodology to provide a different sociology, one that would pay attention to the organization of “commonplace everyday activities” (Garfinkel 1967, p. vii). Ethnomethodology is an approach to the investigation of social life whereby the central focus is to describe *how* people coordinate ordinary social activities in organized recognizable ways and the “doing” of such activities (Garfinkel 1967). Further, Garfinkel (1967) claims that ethnomethodology is the study of actual subject matter that includes the body of common sense knowledge, procedures, and considerations whereby ordinary members of society make sense of and respond to the situation in which they find themselves. It focuses on members’ situated, practical, and methodical achievement of their activities in any given setting. It is vital to note here that the fundamental recommendation “is that the activities are whereby members produce and manage settings of organized everyday affairs are identical with members procedures for making those settings ‘account-able’ (Garfinkel 1967, p. 1). Accountable in this sense refers to observable and reportable activities, as in situated practices of looking-and-telling. The practices performed are undertaken by members who are part of a particular setting whose “skills with, knowledge of and entitlement to the detailed work of that accomplishment-whose competence- they obstinately depend upon, recognize, use and take for granted” (Garfinkel 1967, p. 1). Ethnomethodologists are interested in the way in which members deal with issue of generality and, occasionally, with how in any particular situation generally shared notions and presuppositions can be used to make sense of the actual activity that is occurring.

2.2 Emergence of Ethnomethodology

Philosophical perspectives, including phenomenology, influenced the progression of ethnomethodology and its variants (Schutz 1972). Garfinkel is known as the “founding father” of ethnomethodology. Ethnomethodology stems from its “mother discipline” of sociology and to all social science; therefore, ethnomethodology can be traced back to a definite origin. The detailed historical background to ethnomethodology is beyond the scope of this chapter. In the mid-1950s, Garfinkel invented the term *ethnomethodology*; however, it only became known in the mid-1960s (Lynch 1993). Between 1940s and 1960s, Garfinkel was drawn to social theory, the basic problems of social order, social action, intersubjectivity, and knowledge (Heritage 1987).

The performance by the members and their interaction and construction of social activities are important to any theory of social action. Garfinkel primarily drew on the work of his PhD supervisors, Talcott Parsons and Alfred Schutz, to recommend a new approach to social theory (ten Have 2004). Despite drawing on Schutz’s work, ethnomethodology is not an extension of his work (Holstein and Gubrium 2005).

Pollner (1974) refers to ethnomethodology in terms of “facts are treated as accomplishments,” meaning that they are produced through members’ practical activities, in comparison with classical sociology where the chief aim is to investigate “social facts” and their determinants where the focus is on the actions of the individuals (ten Have 2004). Parsons had a huge influence on the theory of action. Following on, American sociologists were introduced to a range of European theorists such as Durkheim, Weber, Marshall, and Pareto where the focus was on the voluntaristic theory of action. This work was based on the disciplines of sociology, social anthropology, and social and clinical psychology which contributed to the promotion in the development of interdisciplinary research (Heritage 1984).

Garfinkel examined the issues with the theory of action. He focused on the use of actor’s knowledge and understanding within the voluntaristic theory. Garfinkel concentrated on a theoretical framework that directly captures the actions by which actors explore their circumstances and subsequently develop a plan of action. This framework would result in an account of social activity which is directly based on the analysis of the organization of the experience itself (Heritage 1984). According to ten Have (2004), ethnomethodology is very much interested and has a deep respect for the practical and accountability of the most common place of ordinary activities. Overall, ten Have (2004) clarifies that while Weber, Schutz, and Parsons examined idealized models of science and scientific rationality, ethnomethodology examines and studies the local accountability of *any* kind of practice. In so doing, ethnomethodology can show how professional practice is embedded in quite ordinary competencies, as well as elaborates on being part of a particular local version of a more generalized professional culture. Hence, ethnomethodology can be used as a research methodology in health care, including multidisciplinary health personal. Ethnomethodology leans toward the analysis of social life with the central focus being to describe how people put ordinary social activities together in orderly recognizable way while including core concepts of ethnomethodology. The core concepts are accountability, reflexivity, and indexicality.

2.3 Ethnomethodology: Core Concepts

Accountability, reflexivity, and indexicality are the core concepts of ethnomethodology and, in particular, have very special meaning in reference to ethnomethodology and Garfinkel. Garfinkel (1967), in the introductory chapter of *Studies in Ethnomethodology*, states three constituent features that are the “accountability of practical actions as an ongoing practical accomplishment.” These are “(1) the unsatisfied programmatic distinction between and substitutability of objective (context free) for indexical expressions; (2) the ‘uninteresting’ essential reflexivity of accounts and (3) the analyzability of actions-in-context as a practical accomplishment” (Garfinkel 1967, p. 4), more commonly discussed as accountability, reflexivity, and indexicality (Pierce 1991; ten Have 2004; Koschmann 2012).

2.3.1 Accountability

Accountability in Garfinkel's terms does not relate to liability as in ordinary talk, but leans toward intelligibility or explicability. Accountability is looking at actors making sense clearly of their situations and planning action on site, locally and immediately or explicable on demand (Garfinkel 1967; ten Have 2002). Accounts are known as the ways in which members denote or explain the social situation and consist of both verbal and nonverbal reporting. One such example is people who are standing in a line at a bank teller. It is clearly seen that they are doing just that, which is demonstrated by their body position. The members may understand and respond to a question like "Are you in the queue or are you standing in line?" It is noted that the "understandability" and "expressibility" of an activity is a sensible action and, simultaneously, an essential part of that action (ten Have 2004). In addition, the term implies that the basic requirement for all social setting is that it is recognizable and accountable for what it actually represents; it is what it supposed to be (ten Have 2002). According to ten Have (2002), by the members knowingly and visibly performing their role whereby the scenes of their work are accountable, the situation is then organized where reality and meaning are conveyed. Therefore, in terms of accountability from the ethnomethodology perspective, the everyday activities undertaken by members are the methods that make those activities observable and reportable.

Garfinkel (1967) views members as possessing ordinary linguistic and interactional skills through which the accountable features of everyday life were produced. These implicated members in the production of social order, thus working to give their world a sense of orderliness. The focus became members' integral methods for accomplishing everyday reality.

2.3.2 Reflexivity

In his foundational text, *Studies in Ethnomethodology*, Garfinkel (1967, p. 1) pens:

The following studies seek to treat practical activities, practical circumstances, and practical sociological reasoning as topics of empirical studies, and by paying to the most commonplace activities of daily life the attention usually accorded extraordinary events, seek to learn about them as phenomena in their own right their central recommendation is that the activities whereby members produce and manage settings of organized everyday affairs are identical with members' procedures for making those settings 'account-able.' The 'reflexive' or 'incarnate' character of accounting practices and accounts make up the crux of that recommendation.

Garfinkel (1967) uses reflexivity to focus on the above-specific property whereby the expression of an activity is a vital part of that activity, especially of ordinary actions. The members use the reflexivity of accounts to give meaning and sense to orderliness in a social setting. Hence reflexivity ties in with the self-explicating property of ordinary actions, thus exploring subjective social meaning through an individual's lens.

2.3.3 Indexicality

Indexicality is a key concept for ethnomethodology. Garfinkel (1967) claims that indexicality was derived from the concept of indexical expressions which appear in ordinary language. The meaning of indexicality and sense making is embedded and dependent upon the context of the local situation (Bar-Hillel 1954). For Garfinkel, indexicality is more than context-dependent and includes a sense of “particular,” which refers to action in a definite situation that produces meaning or sense. The meaning or sense making is linked to particular contexts and cannot be understood outside of that situation or local circumstance (Garfinkel 1967; ten Have 2004). Further, a phrase that would make sense in one context in an interaction might seem ironic when used at another point. Actors within a particular context create indexical expressions, words, facial and body gestures, and other cues to maintain the presumption that a particular reality governs their affairs (Garfinkel 1967; Heritage 1984). For example, simple expressions like “you” can be thought of on all occasions and actions are in fact indexical, in the sense that it could hold different meanings in different contexts. Without context, it is not possible to generate meaning.

The above key concepts of ethnomethodology, namely, indexicality, reflexivity, and accountability together, have shown meaning as a methodical accomplishment. The key concepts do not stand alone but are mutually interdependent of actions and contexts, thereby producing, reflexive accountability of action thus resulting in the orderly and organized setting.

2.4 Member Categorization and Conversational Analysis as the Two Sacksian Notions

In the later development of ethnomethodology, membership categorization analysis (MCA) was a term that Sacks (1972) used in his early work in the organization of knowledge which relied on and displayed as local interactions. According to Sacks, such knowledge was organized in terms of categories of people, for example, as in “children” or in reference to the speaker, as in “my husband” and actions. A common description that Sacks mention is “The baby cried. The mommy picked it up” (Sacks 1992, p. 236), which shows the interaction of members. The beginnings of such insights and broad explications arose out of Sack’s PhD research on calls to a suicide prevention center (Sacks 1972) where callers explained life situations and how they felt especially in terms of no one to look to for support (Sacks 1967). In addition, people used person categories, which took the form of a collection of categories, for example, baby, mother, and father belong to the family, which Sacks called membership categorization devices (MCD) (Sacks 1972). Moreover, in reference to gender, there are two categories, “female” and “male.” Further MCDs have a team or relational implication, for example, “the doctor and patient or teacher and student.” Therefore, membership categorization analysis is useful in the study of the social knowledge that people use, expect, and rely on in doing the accountable work of living together (ten Have 2004).

The other term Sacks's work included is sequential analysis which forms the basis for conversational analysis (CA). Practice in everyday life through language is central to ethnomethodology as highlighted by Pomerantz (1988, p. 361):

Ethnomethodologists and conversation analysis seek to discover the interpretive practices through which interactants produce, recognize, and interpret their own and others' action.

See ► [Chap. 28, "Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis"](#) for more detail about this analysis method.

3 How Ethnomethodology Is Done

This section discusses the ways in which ethnomethodology research is undertaken. In social science, ethnomethodology is best known for Garfinkel's early "breaching experiments" and the use of recordings and transcripts in conversational analysis (1967).

3.1 Ethnomethodology and Common Sense Procedures

The focus of ethnomethodologically research is primarily on naturally occurring data in the everyday life practical activities versus researcher provocation data. As ethnomethodology pays attention to the study of procedures of common sense as it is used in actual practices, there are methodological problems. Members take on a practical sense rather than a theoretical awareness of their constitutive work, and in so doing, it is possible to take common sense and their constitutive work for granted, unless attention is drawn to an untoward issue (ten Have 2004). According to Zimmerman and Pollner (1971), the concern with ethnomethodology is how common sense practices and knowledge risk lose their status as an unexamined resource so as to become a "topic" for analysis. Initially, to create this scenario, an approach Garfinkel initiated was to "breach" expectations to cause "trouble" (Garfinkel 1967). The breach expectancies of actors in the midst of action of their intersubjective environments are to "deliberately modify scenic events to disappoint these attributions" (Garfinkel 1967, p. 57). Therefore, it is important to find practical solutions, which are unavoidable compromises.

There are four strategies primarily in Garfinkel's early work, namely, sense-making activities; researchers study their own sense making, closely observing situated activities; and the study of ordinary practices. Together, the above strategies tend to work best. The first three strategies make use of literal quotes as seen in Garfinkel's (1967) reports on experiments, while more recent studies, recordings, and transcripts tend to be used (Garfinkel et al. 1981; Lynch 1985). Ethnomethodology and the "visibility problem" are in part solved by the creation or selection of "strange environments," and one such environment is the workplace.

Ethnomethodology uses two phases in the research process because the use of sense making is inevitable. This means that the researcher will use "member's sensemaking practices" to understand the activities and secondly analyze the "methods used in the first phase as one's research topic" (ten Have 2004, p. 53).

3.2 Breaching

According to ten Have (2004), the term “breaching” as used by Garfinkel referred to the use of experimental demonstrations in which covert expectations were breached. In other words, it is where actors would intentionally “break” norms and rules to see the reactions of others (Garfinkel 1967). It is the violation of socially accepted common rules or norms that may be used to maintain order. It is important to note here that the term experiment does not in any way indicate cause-effect according to Garfinkel (1967), and only some were undertaken in a laboratory. Such experiments were performed by Garfinkel’s students in the field. An example “Students were instructed to engage an acquaintance or a friend in ordinary conversation and, without indicating that what the experimenter was asking was in any way unusual, to insist that the person clarify the sense of his commonplace remarks” (Garfinkel 1967, p. 42). The breaching experiments can be seen as efforts to make the workings of common sense visible.

4 Data Collection Techniques: Gathering Information

Ethnomethodology is dependent primarily on video-recorded data. Below is a discussion of various data collection techniques.

Digital recordings and transcriptions dominate ethnomethodological data collection. It is very much attuned to the use of recordings of actual, naturally occurring data and social interaction, orienting to them as constitutive elements of the setting studied (Sacks 1972; Mehan and Wood 1975; Atkinson and Drew 1979; Maynard 1984; ten Have 2004). Recordings and transcriptions are clearly demonstrated in conversational analysis and used to record original events (ten Have 2004). Tape-recorded conversations allow for the detail of the actual human action, which is then subjected to close scrutiny and formal analysis (Sacks 1984). In this instance, it has taken different empirical directions and depended on whether the interactive meaning or the structure of talk is being emphasized (Holstein and Gubrium 2005). Studies that emphasize the structure of talk examine the “conversational” analysis (CA) through which meaning emerges (see ► Chap. 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”).

Interviews are the most common technique used to collect data in qualitative research, more so for social researchers (ten Have 2004; see also ► Chap. 23, “Qualitative Interviewing”). On the contrary, in ethnomethodological studies, interviews are not the method of choice to collect data case despite ethnomethodology being used to explore talk with people or listen to what people have to say. In interviews that are performed traditionally, interest is in people, like individuals, categories, or collectivities of persons, including their characteristics, value, orientations, motivations, experiences, and relations, hence most often refereeing to the properties of people. The goal here is to explore what people think, feel, or experience or a combination, and the response is formulated in their mind. On the contrary, ethnomethodology’s interest is in people as *members* and as competent practitioners, because ethnomethodology is interested in order-producing *practices* and can be further narrowed to *procedures* of

order production; therefore, ethnomethodology is interested in the *how* (Garfinkel 1967; ten Have 2002). Moreover, these practices are seen as specifically local and situated. Even though this order-producing practice may have general features, the overall effect is context sensitive, and the reality to be studied in ethnomethodology is a local accomplishment of member practices. Due to these issues, interviews are of limited use in ethnomethodology. Ethnomethodology studies naturally occurring situations in which practices are observable and reportable (Garfinkel 1967; ten Have 2004).

5 Ethnomethodology: Compatibility and Use with Other Methodologies

Overall, ethnomethodology is not compatible with other methodologies, even though aspects have been drawn from phenomenology. Ethnography and ethnomethodology may appear to be related to each other in complex ways whereby ethnomethodology will need ethnography, verbal depictions, and characterizations of events in particular places and times (ten Have 2004).

Ethnomethodology and conversational analysis (CA) are commonly used in organizational and workplace studies. Conversational analysis developed from ethnomethodology and analyzes interactional social behavior and talk-in-interaction (Silverman 1998; ten Have 1999). Ethnomethodology and conversational analysis share some principles according to Clayman and Maynard (1995). For example, talk and social actions are considered “indexical” because their understanding is context driven and commonly used in workplace studies (see also ► Chap. 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”). Workplace studies are a naturalistic approach. It is where the details of interaction, talk, and workplace practices are explored in terms of how procedures, activities, and tasks are performed in real-time interaction, through talk and visual conduct (Heath and Luff 2000; Luff et al. 2000).

Although ethnomethodology and ethnography are not frequently combined to undertake research, according to ten Have (2004), ethnography does hold some vital virtues, especially when field recordings are used to collect data. The use of field recordings contributes to the viewing of embodied action and context character of human existence. This is evident when ethnographic studies use ethnomethodological methods to produce accounts of people’s methods in everyday practical situations (Collins and Makowsky 1978). The study by Whalen and Vinkhuyzen (2000) highlights the use of ethnomethodology and ethnography, making it a multifaceted ethnomethodological ethnographical study, using transcribed phone interactions and screen displays to illustrate the findings.

6 Ethnomethodology: Weaknesses and Limitation

Ethnomethodology is not alone when it comes to weaknesses and limitations. It is noted that ethnomethodology has some essential methodological problems. According to ten Have (2004), some of the problems arise due to the fact that with

ethnomethodology the phenomena of interest and sensemaking practices are hard to note in ordinary situations, because they are constitutive (intrinsic) of those very situations and unavoidably used in any research practice itself. ten Have (2004, p. 51) refers to the essential methodological problems as “the invisibility of common-sense.”

As video data is the most preferred data collection method, it can be a challenge. This data collection method can be a hindrance in some cultures and in some practices in health. For example, if additional team members walk into the operating theater, unknown to them that recording is in session, the individual will need to be informed and consent obtained retrospective or the clip from the video data deleted if the individual disapproves or declines to provide consent. Ethnomethodology is also identified as lacking in a defined analysis process even though the practical events are observed and reported.

The limitation would be a challenge when using the ethnomethodological approach in cultures where faces of family members who have died may cause harm. Yet, another aspect is the limitation of the use of interview data. Interview data collected here would be a recollection of the account of an event; hence the practical action in the context of occurrence is not observed. Ethics in the breaching process is questionable.

7 Ethnomethodology: Strengths and Advantages

There are strengths and advantages to using ethnomethodology as a qualitative research process (Atkinson 1988). Ethnomethodology is a methodology that focuses on an area often overlooked in health care: the cultural influences on medical care delivery and how patients perceive and understand their interactions with their doctor, their disease, the examination room, and, possibly, with a third actor in the examination room, the computer. The data collected using video recordings are an advantage as the data can be viewed many times over by the researcher as well as other team members so as to meet rigor (Heritage and Atkinson 1984). Ethnomethodology prevents researchers depending on intuition and recollection for the analytical process but on what is actually observed. The researcher is exposed to a wide range of local interactional material and circumstance. Analytical conclusions will not arise as artifacts of intuitive idiosyncrasy or experimental design. The additional advantage with video-recorded data is that researchers hear the data and see interaction rather than read the research reports. The researcher has direct access to the data, and the data is available for public scrutiny. Tapes and transcripts have both heuristic and confirmatory functions (ten Have 2004; Heath et al. 2010).

8 Practicalities of Using the Methodology

According to ten Have (2004), any activity can be studied at real time in naturally occurring environment where order is created. Ethnomethodological studies focus on observation and note what is actually going on without the use of a traditional theoretical framework or rather by bracketing what is already known.

Like any other research design, ethnomethodology requires ethical approval, which can be a challenge due to the main data collection technique as mentioned earlier, video recording. According to ten Have (2004), research students were embarrassed to show their lack of knowledge and confidence in the use of a video camera and expected to encounter a number of objections from people who were being observed. Researchers must familiarize themselves with the use of a video camera, which can be complex as every detail is important. It is necessary to ensure that the spoken language is clearly captured. The video recordings capture interactional details like facial expressions, gaze direction, and embodied interaction. Once the recordings are completed, transcriptions of the video data must be undertaken. The researcher is required to up skill in the use of technology as editing, clips, and still photographs may be required from the large corpus of data, which can be immensely time consuming.

Access to study-specific activities may be a challenge because ethnomethodology studies the accomplishment of concrete lived orders (ten Have 2004). Ethnomethodological researchers ensure that rapport is established with organizations and that they are aware of the requirements necessary to obtain access to the complex local order-producing activities. The researchers have to choose the setting and the activities that they desire to focus on. The researcher has to consider the activities to be studied and has to construct ways for the “data” to be represented.

9 Ethnomethodology in Action

The use of ethnomethodology varies across a span of disciplines and more recently being utilized increasingly in workplace studies. Bezemer et al. (2011) performed a study that focused on how surgical work is accomplished in the operating theater. Bezemer et al. (2011) aimed to explore the interaction and organization of activities between surgeons and nurses in the operating theater and included how social interactions are used to help structure and define situations. In addition, the study included how the members’ differences in knowledge are constructed and positioned. In this study, video data was recorded, and the authors used concepts from symbolic interactionism, ethnomethodology, and conversational analysis to study small clips from the video recordings. In yet another study, Svensson et al. (2009) performed a study in operating theaters on how demonstration and instruction are achieved and made accessible to trainees to witness and learn techniques and procedures in specific cases while maintaining the integrity of medical practice in highly complex and demanding procedures. The authors claim that social interaction or interaction with patients, colleagues, and other staff is the key to learning how to achieve activities when delivering health care that combines specialized activities in concert with others in ordinary everyday situation.

Ethnomethodology extended to aviation, whereby Nevile (2004) undertook a study between pilots in the cockpit of commercial aircraft. The study focused on the communication pilots engaged in with colleagues, team members, and other parties like traffic controllers during routine checks that is required in flying an

aircraft. Audio and video recordings were used as data collection method, and the author drew on the analytical approaches of ethnomethodology and conversational analysis. The research demonstrated that the pilots' work activities in the cockpit are accomplished through talk.

Further the work of ethnomethodology may be applied in playing the game (Kew 1986) and young children's play (Butler 2008). Moreover, within education, ethnomethodological approaches have been used to examine how lessons get done interactionally (Mehan 1979).

10 Conclusion and Future Directions

Ethnomethodological approach has the potential to contribute to the manner in which organizational studies are done, thus contributing to research, focusing on the practical activities of the everyday among members. Ethnomethodology focuses on people's tacit resources of social action, their common sense, and interactional activities with other members. Within this approach, the researcher requires additional technical skills to enhance data collection with the use of video recording, a technique that provides a rich corpus of data. Institutional studies, more often referred to as workplace and organizational studies, benefits largely from the use of ethnomethodology to understand the *how* of practice, specifically among multi-disciplinary team members to perform a joint activity. Unique to ethnomethodology are the terms accountability, reflexivity, and indexicality, especially where practices are specific to context. Ethnomethodology and the cross-disciplinary studies can contribute richly to research in various fields including health team, aviation child play, and more.

Ethnomethodology, despite being used widely currently, is still considered to be underused. In relation to future direction and applications, it is proposed that ethnomethodology be included in the research unit to provide a view of the rich data collected and varying analysis compared to traditional research methodology. In health care, ethnomethodology has the great potential to contribute greatly to enhance patient safety by observing the interaction of multidisciplinary members and the construction of an activity with a view to improving practice. In addition, ethnomethodology contributes to team interactions and potential improvement because researchers can observe how communication and interactions occur and then note room for improvement.

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Community-Based Participatory Action Research

17

Elena Wilson

Contents

1	Introduction	286
2	Conceptual Foundations	288
3	Community Participation	289
4	Power Equilibrium	290
5	Social Justice and Equity	291
6	Practice of CBPR	291
6.1	Research Process	291
6.2	Phases of CBPR	291
7	Researcher Role	294
7.1	Partnership Expectations	294
7.2	Training	294
8	Methodological and Ethical Considerations	295
9	Conclusion and Future Directions	295
	References	296

Abstract

Community-based participatory research (CBPR) is regarded as an equitable research approach that is operationalized within a social justice framework. It has been referred to as a continuum of research approaches from action research to participatory action research. Researchers are increasingly drawn to CBPR for collaborative health research that values community participation to redress issues of health inequality arising from socioeconomic disadvantage. Distinguishing features of effective CBPR include: blurring the distinction between researchers and research participants, minimizing power imbalances, and researching in partnership with communities towards positive community

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outcomes that are sustainable beyond the life of the research. Inherent complexities of communities and partnership arrangements can, however, lead to methodological and ethical challenges for researchers. Recent studies have found this to be the case, pointing to the need for adequate training and preparation for researchers who are new to CBPR. The intention for this chapter is to provide an overview of the conceptual foundations of CBPR and practical guidance for operationalizing each phase of the research process, while raising awareness of important considerations for the researcher role, from seeking ethics approval and entering the community, to dissemination of results. Drawing on international studies, lessons learned from experienced CBPR researchers are summarized so that researchers new to CBPR can build on their understanding and strengthen their studies in the future.

Keywords

Community-based participatory research · Social justice · Equity · Participatory methods

1 Introduction

Participatory action research (PAR) and Community-based participatory research (CBPR) can be understood as collaborative approaches to research that aim to achieve social change (Israel et al. 2013; Minkler and Wallerstein 2008). While various terms are used to label collaborative research across different disciplines, there is no commonly agreed definition for research with a community participation component (Brydon-Miller 1997; Wallerstein and Duran 2010). Because of the lack of definitional clarity, the relationship between PAR and CBPR described by Minkler and Wallerstein (2008) is useful as a foundation for discussing CBPR in this chapter.

Community-based participatory research (CBPR) is described by Minkler and Wallerstein (2008) as an umbrella term that refers to an orientation to research and practice in which the focus is respectful engagement with communities while combining research with education and action for change (see also Hall 1981). CBPR is, hence, understood as a continuum of approaches to research rather than a research method. Minkler and Wallerstein (2008) suggest that CBPR ranges from action research to PAR, with participation gradually increasing from narrow participation towards full participation. Action research sits at the starting point of the continuum and involves people who are affected by a problem in practical problem solving. At the other end of the CBPR continuum, referred to by Minkler and Wallerstein (2008, p. 10) as the “emancipatory end,” is the “gold standard” of full participation as the aim for researchers whose goal is to achieve social justice, particularly in redressing health disparities (Minkler and Wallerstein 2008, p. 11). A commitment to engagement and power-sharing with community partners in the research process so that communities benefit from the research (Israel et al. 2013) is present at all levels on the CBPR continuum.

Growing support for CBPR has seen it extensively used in qualitative health research and other disciplines such as geography, archaeology, and education (Minkler and Wallerstein 2008; Atalay 2012; Castleden et al. 2012; Hacker 2013). CBPR is recognized for its utility in research on health disparities that result from systemic disadvantage. It is, therefore, often used to explore issues such as poverty, racism, and forced migration in research with communities of people living with mental illness, refugees, and rural populations (Hacker 2013; Vaughn et al. 2016).

CBPR is an approach to research that is used to achieve a shift in emphasis from victimization to strengths that take into account personal lives and controlling structures (Minkler and Wallerstein 2008; Israel et al. 2013). Central to CBPR is the concept of community participation requiring a redistribution of power with the aim of producing benefits for the community (Blumenthal 2011). It is iterative and evolving and is distinguished by its emphasis on involvement of the community as co-researchers (Wallerstein and Duran 2010).

Although each CBPR project is unique (Israel et al. 2013), community participants are generally involved in decision-making from project conception to dissemination of results. CBPR includes the need to acknowledge community as variously conceptualized and to attain social equality through power sharing (Israel et al. 2013). Action and social change are, hence, promoted through cyclical, iterative, and sustainable processes (Israel et al. 2013). Despite widespread support for CBPR, there is a growing body of international literature that draws attention to methodological and ethical challenges associated with its operationalization (Banks et al. 2013). Some of these challenges will be considered in this chapter.

For researchers who aim to achieve a more equitable and just society, a CBPR approach is believed to be the most valuable (Mayan and Daum 2016). CBPR has been used successfully by researchers seeking to work collaboratively with Indigenous communities (Wallerstein and Duran 2010; Atalay 2012). Funding for health research is increasingly contingent on the inclusion of participatory approaches in the research design (Burke et al. 2013; National Health and Medical Research Council (NHMRC) 2016). Funding bodies, in national and international arenas, are increasingly requiring participatory approaches in health research. Funding of CBPR projects has been made available by agencies in the United States, such as National Institutes of Health (NIH) and Centers for Disease Control and Prevention (Burke et al. 2013), and in Australia, funding is available from the National Health and Medical Research Council (NHMRC). Researchers who apply for NHMRC funding to its Centres of Research Excellence scheme are required to demonstrate broad community participation in the research (NHMRC 2016). This is based on the NHMRC's recognition that the valuable insights provided by community participation in research contributes to its quality and direction (NHMRC 2016).

In this chapter, I introduce the conceptual foundations of CBPR with specific reference to: community participation; power equilibrium; and social justice and equity, followed by considerations for effective practice of CBPR. Aspects of the researcher role are briefly discussed with reference to partnership expectations and researcher training, after which attention turns to introducing methodological and ethical considerations for researchers wishing to use the CBPR approach.

2 Conceptual Foundations

The development of CBPR is founded on the action research approach advanced by Lewin (1946) and later the emancipatory ideals of Freire (1970). Connecting applied social science and social activism, their work developed towards a new paradigm of participatory research, (Minkler and Wallerstein 2008). CBPR evolved from the two different research traditions.

Utilitarian views of Kurt Lewin in the 1940s, rejected positivist approaches grounded in objective truths arguing rather for people's collective involvement in researching their own circumstances (Wallerstein and Duran 2008). Lewin promoted a collaborative problem-solving research cycle of planning, action, and evaluation (Wallerstein and Duran 2008). Knowledge produced in this way would be used for practical goal-oriented action. Lewin referred to this process as *action research* (Wallerstein and Duran 2008).

In his 1970 publication *Pedagogy of the Oppressed*, Paulo Freire who expressed his view of liberation through education, inspired a later research tradition based on a philosophy of transformative praxis (Wallerstein and Duran 2008). A climate of political unrest and social inequality in South America saw Freire respond by advocating love, trust, and relationality as central to the process of humanization and education towards revolutionary change (Wallerstein and Duran 2008). Freire's faith in humanity and people's role in making change was driven by a social justice agenda, leading Freire to the belief that when supported, rather than directed, by intellectuals, the powerless can take action towards their own liberation through consciousness raising (Freire 1970; Israel et al. 1998; Wallerstein and Duran 2008).

CBPR is influenced by critical theory often based on Habermasian utilitarian problem solving, normative social and cultural values, and emancipation (Habermas 1971; Wallerstein and Duran 2008). Subsequent influences were theories of feminism, poststructuralism, and post colonialism (Minkler and Wallerstein 2008). Thus, the focus of methods and goals of CBPR, influenced by social movements of the 1960s and 1970s in search of a fairer society, became social justice and challenging the idea of science and objectivity (Minkler and Wallerstein 2008; Israel et al. 2013).

Over the last two decades, the use of the term CBPR and application of this approach have grown rapidly in several fields, but most noticeably in the health field (Wallerstein and Duran 2008). The adoption of CBPR in different disciplines has resulted in several variations of the term CBPR, such as, community-partnered participatory research, participatory research, and rapid rural appraisal. The term CBPR has also been used with specific emphasis, such as tribal participatory research (Wallerstein and Duran 2008).

A number of sets of principles to guide the CBPR research partnership have been proposed (Israel et al. 1998, 2013; LaVeaux and Christopher 2009). Frequently cited principles for conducting CBPR are those developed by Israel et al. (1998). The principles were published with the caveat that "no one set of CBPR principles is applicable to all partnerships" (Israel et al. 2013, p. 8). The principles have evolved and will continue to evolve as research continues to be conducted and evaluated (Israel et al. 2017). The current CBPR principles are:

1. CBPR recognizes community as a unit of identity.
2. CBPR builds on strengths and resources within the community.
3. CBPR facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequalities.
4. CBPR promotes co-learning and capacity building among all partners.
5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.
6. CBPR emphasizes public health problems of local relevance and ecological perspectives that attend to the multiple determinants of health and disease.
7. CBPR involves systems development through a cyclical and iterative process.
8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
9. CBPR requires a long-term process and commitment to sustainability.
10. CBPR addresses issues of race, ethnicity, racism, and social class and embraces “cultural humility” (Israel et al. 2017, p. 30–33).

Israel et al. (2017, p. 29) propose that CBPR is ultimately an integration of all of these individual principles and that the extent to which any combination of these principles are achieved “. . . will vary depending on the context, purpose, and participants involved.” As the principles are considered to be situated on a continuum, they are presented as a goal towards which to strive rather than standard practice (Israel et al. 2017) as in reality, it would be rare to achieve “pristine CBPR” (Blumenthal 2011, p. 388).

3 Community Participation

Equitable participation of community partners at each stage of the research is foundational to CBPR (Blumenthal 2011). In the absence of a common definition of community participation, it has been described as a concept that emerged out of the desire to redress inequality through collective public action and attend to issues about power and control (Rifkin 2014). Arnstein’s (1969) typology of community participation is based on different degrees of power sharing, represented as a ladder of participation, on which *manipulation* appears on the lowest rung, progressing through to *citizen control* at the highest level in which government power is transferred to citizens. If community participation is understood as being on a continuum, it can be applied in CBPR with the aim of achieving “maximum feasible community participation” (Buchanan et al. 2007, p. 153).

The degree of community participation in the early phase of CBPR has attracted discussion about whether CBPR projects can all be initiated by the community (Mosavel et al. 2005; Minkler and Hancock 2008). Topics for investigation in CBPR projects ideally originate in the community (Mosavel et al. 2005). For academic researchers accustomed to traditional research approaches, this represents a major paradigm shift (D’Alonzo 2010). In reality, however, time, expertise, and

funding for the research study means that many CBPR projects are initiated by the researcher (Minkler and Wallerstein 2008; D'Alonzo 2010; Castleden et al. 2012). In such cases, it is essential that a genuine commitment be made to involve the community and determine in the early phase whether the proposed research topic is a priority for them (D'Alonzo 2010).

Community members sometimes participate in CBPR studies as co-researchers (also referred to as field assistants or community research workers). This type of participation directs involvement away from passive interactions between traditional notions of *subject* and *researcher* that can signal exploitation (Bromley et al. 2015). Co-researchers usually live or work in the partnering community and participate in the research with institutional researchers in a range of ways that might include translating between community members and academic researchers, assisting with recruitment, and administering surveys (True et al. 2011). Because co-researchers can bring local knowledge and cultural understanding to the partnership, they are able to facilitate access to community members through their social ties and common perspectives that link them to the community (True et al. 2011).

4 Power Equilibrium

CBPR challenges traditional power relationships between researchers and researched reinforcing partnership for mutual benefit (Wallerstein and Duran 2017). Genuine attempts at CBPR call for researchers to understand power differentials within partnerships, such as, race, gender, and class and practice a relinquishing of the traditional dominant model of power associated with research to achieve a redistribution of power across all who are involved in the research (Minkler and Wallerstein 2008). Power sharing among partners is foundational to CBPR particularly in relation to decision-making (Viswanathan et al. 2004; Minkler and Wallerstein 2008) and reflects the three interconnected goals of research, action, and education (Hall 1981; Wallerstein and Duran 2008).

Scholars emphasize the importance of researchers employing cultural humility to redress power imbalances (Tervalon and Murray-Garcia 1998). Cultural humility is understood as a lifelong commitment to egoless self-evaluation and self-critique in partnership development and maintenance based on mutual respect and trust (Tervalon and Murray-Garcia 1998; Foronda et al. 2016).

Reciprocal knowledge transfer can also lead to a greater balance of power recognizing value in the knowledge of all members of the partnership (Wallerstein and Duran 2008). Power gained through reciprocal knowledge transfer can facilitate the community's liberation from "the social structural factors that have historically silenced its voices" (Muhammad et al. 2017, p. 108) thereby enriching each partnership member's understanding of the world (Wallerstein and Duran 2008, 2017). This type of knowledge democracy has the effect of recovering knowledge that lies in the expertise found in the world "beyond academia" (Hall et al. 2015, p. 2).

5 Social Justice and Equity

CBPR is useful to researchers who seek to advance social justice goals of equity and knowledge democracy, develop respectful relationships, and influence policy for health equity (Banks et al. 2013). Braveman and Gruskin (2003, p. 254) define equity in health as “the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage – that is, different positions in a social hierarchy.” Social justice goals can be achieved through a commitment to inclusive practices that promote equity of opportunity to participate. Researchers play an important role in facilitating participation so that those community members who are usually disengaged might have ways to be involved. Achieving social justice and health equity using CBPR involves sustainable outcomes, that is, members of the partnership work towards outcomes that can be sustained beyond the life of the research.

As an emancipatory approach, CBPR is often used in research seeking to address health disparities and vulnerability resulting from structural inequality and institutional racism (Muhammad et al. 2017). As Minkler (2004, p. 691) suggests, “we can approach crosscultural situations with a humble attitude characterized by reflection on our own biases and sources of invisible privilege, an openness to the culture and reality of others, and a willingness to listen and continually learn”.

6 Practice of CBPR

6.1 Research Process

The increasing health disparities affecting minority groups globally render CBPR a defensible choice for researchers and communities (Chavez et al. 2008). CBPR can also accommodate the growing trend of communities that wish to participate in researching and solving their own problems (Hacker 2013). There is, however, no definitive process for conducting research using a CBPR approach.

6.2 Phases of CBPR

Rather than rigid adherence to a set of steps in a process, CBPR involves phases between which the research team and partnership members move. Israel et al. (2013) describe seven phases of conducting CBPR: Form a CBPR partnership; Assess community strengths and dynamics; Identify health priorities and research questions; Design and conduct research; Feedback and interpret findings; Disseminate and translate research findings; and Maintain, sustain and evaluate partnership. In these phases, the emphasis is on diverse partners and researchers seeking to achieve equal participation and ownership of the research. The process is circular and, therefore, iterative with some elements that can be ongoing, such as partnership

maintenance (Israel et al. 2013). The following paragraphs highlight the main elements within each phase.

Form a CBPR Partnership: For community participation to be effective, partnership members must firstly define what constitutes *the community* for the purposes of the research. Defining the community can be by geographic location, health condition, common characteristics, or can be self-defined (Viswanathan et al. 2004; Hacker 2013). Identifying potential partners with which to develop operational infrastructure and establishing partnership expectations requires building trust and relationships. Groups most impacted by health disparities need to be involved in the design and implementation of strategies to address the community issues locally (Chavez et al. 2008; Israel et al. 2013).

Assess community strengths and dynamics: Each research partnership and setting is unique. Before following or adapting CBPR principles for distinct contexts, local issues need to be carefully considered (Israel et al. 2017). Therefore, it is necessary to study the community's demographic, social, and political landscape; meet with leaders of active community groups; and identify relationships and connections (Hacker 2013). Lack of trust between researchers and community members is widely acknowledged as a common difficulty (Israel et al. 1998). Building trust and building relationships is important and requires an ongoing commitment by researchers to demonstrate their trustworthiness and being sensitive to potential community impacts caused by research involvement (Israel et al. 1998; Austin 2015). A community advisory board or committee might need to be established or there might be a preestablished group in the community. This group will be important for participating and liaising with the community about the research and can contribute to the success of the project by providing guidance about community matters to the researcher (D'Alonzo 2010; Hacker 2013). Similarly, key local stakeholders can be helpful as boundary crossers for partnership success because, as local residents who are also working on the research, they can bridge the gap between the researcher and the community (Kilpatrick 2009; D'Alonzo 2010). As they are part of the community, they will have "insider" knowledge about acceptability of practices involved in the research and can help to legitimize the research by building perceptions in the community that the research and the researchers involved can be trusted (D'Alonzo 2010). These activities are time intensive and must be conducted in a participatory manner and with mutual respect within the partnership (Minkler and Wallerstein 2008; Hacker 2013). The process of going in to the community to meet people and learn the culture needs to be accounted for in research timelines (D'Alonzo 2010). Knowing the community and its cultural context can assist with tailoring recruitment methods and materials to fit the community. Recruitment might not be a one-time exercise but can be ongoing as community members dip in and out of the research as the cycle of everyday life allows.

Identify health priorities and research questions: Identifying health priorities involves researchers and partnership members working together to recognize health issues that they are sufficiently concerned about and that they want to explore and take action on (Minkler and Hancock 2008). The health priority needs to appeal to

a broad range of community members and thereby be consistent with their collective vision for a healthy community (Minkler and Hancock 2008). CBPR researchers provide their skills to develop questions intended to lead to social change for improved community health and well-being (Minkler and Hancock 2008).

Design and conduct research: There is no single design or method suitable for all CBPR studies (Viswanathan et al. 2004; Wallerstein et al. 2017). Decisions about data collection methods to be used require respectful negotiation as the researcher must maintain a balance between community wishes and upholding research integrity (Hacker 2013). When choosing the research methods to be used, researchers need to consider several factors including community relations and capacity, financial resources, and time limitations (Vallianatos et al. 2015). A combination of qualitative and quantitative methods can be used in CBPR. Qualitative methods utilized can include interviews, focus groups, photovoice, and observation (see ► Chaps. 23, “Qualitative Interviewing,” and ► 65, “Understanding Health Through a Different Lens: Photovoice Method”).

Feedback and interpret findings: Academics and community partners are mutually dependent and with adequate training, the community can assist with collection and interpretation of data. Identifying initial themes, for example, can be facilitated through creative strategies and can lead to greater research relevance for the community (Hacker 2013; Israel et al. 2013). Research findings can be shared with the community in a culturally appropriate feedback format and setting. Making meaning from the research findings is also a collaborative activity with the participation of all partnership members (Israel et al. 2013).

Disseminate and translate research findings: Dissemination strategies can contribute to sustainable outcomes after project completion. CBPR is essentially translational, meaning that research findings lead to action applied in the community for health or environmental benefits and to build community capacity (Minkler and Wallerstein 2008; Hacker 2013; Israel et al. 2013). Commitment to action is part of the research process and involves community partners taking the lead in identifying future actions to be taken (Minkler and Wallerstein 2008; Hacker 2013). It is an important aspect of CBPR partnerships to address issues of data ownership, such as shared data ownership and how the data will be used (Minkler and Wallerstein 2008). Dissemination of results can take multiple forms and might include community forums for data presentation and discussion of recommendations, formal reports, academic publications, and conference presentations (Hacker 2013). In addition to considerations of who owns the data, questions about co-authorship and co-presentation also need to be addressed (Israel et al. 2008). There is potential for researcher and community agendas to conflict, particularly about timing of dissemination activities (Hacker 2013). Any such conflicts can be managed using open and transparent communication based on flexibility and willingness to respond (Israel et al. 2008).

Maintain, sustain and evaluate partnership: Using CBPR involves a commitment to address inequalities with partnering communities for the long-term. This phase is an ongoing process that through establishment and maintenance of trust in the partnership leads to sustainable relationships and action, often extending further than a single project or funding period (Israel et al. 2008).

7 Researcher Role

7.1 Partnership Expectations

In CBPR partnerships, between community members, organization representatives, and academic researchers, it is ideal for all members to participate fully and share equal control in decision-making (Minkler and Wallerstein 2008). Transparency about partnership expectations is needed for full and equal participation in CBPR (Hacker 2013). Hence, it is vital that the researcher's role and responsibilities for research design and conduct are clearly articulated prior to the researcher entering the community, in addition to the expectations from community members, organizations, and all involved in the partnership. Clarity about expectation help ensure that agreed pathways exist for addressing potential social, cultural, or political problems, thereby avoiding reliance on power dynamics to unfold towards a resolution (Hacker 2013; Wilson et al. 2017). Diversion from the planned process can be necessary, however, as CBPR and partnership processes are not linear but dynamic (Banks et al. 2013). Flexibility is key in avoiding partnership tensions, ensuring that agreed expectations about the researcher's role and responsibilities can be repeatedly reviewed and renegotiated as processes unfold (Banks et al. 2013).

7.2 Training

Conducting CBPR requires a high level of skill and responsibility to achieve ethical conduct of research with collectivities as well as individuals (Bastida et al. 2010; Banks et al. 2013; Carter et al. 2013). The complexities involved in managing a relationship with partner organizations and community highlight the importance of training for CBPR researchers prior to commencing contact with members of the community they are to research with. Yet, Hacker (2013) points out that the number of researchers with adequate CBPR training does not meet the increasing demand for CBPR researchers. Being armed with knowledge and practical training researchers new to CBPR have a greater opportunity for the best possible outcomes for the research. Understanding processes in theory alone are not always adequate as preparation for CBPR processes in practice (Wilson et al. 2017). Researchers need robust practical training in CBPR processes and ethics, while developing the personal awareness and skill needed for working with complex group dynamics (Chenhall et al. 2011; Castleden et al. 2012). The importance of training researchers to achieve authentic CBPR lies also in the need for developing cultural humility that builds awareness of differences in power and privilege and the hidden mechanisms perpetuating racism in social relations (Muhammad et al. 2017). Therefore, with appropriate training, CBPR researchers can achieve and better understand the disrupting role that equitable partnerships play in confronting issues such as systemic racism (Muhammad et al. 2017).

8 Methodological and Ethical Considerations

To achieve the goal of equitable participation of community partners at each stage of the research in CBPR requires greater attention to ethical considerations (Blumenthal 2011). To be noted, however, are the increasingly identified ethical issues that have coincided with the growing popularity of CBPR. The nature of ethical challenges experienced by CBPR researchers can vary between different projects and can often be attributed to the relational nature of the approach. The openness of close relationships inherent in CBPR inevitably conflicts with the duty to maintain confidentiality and anonymity of participants (Brugge and Cole 2003).

Challenges might arise for researchers who deal with CBPR projects on sensitive topics, the content of which parallels their own life circumstances (Carter et al. 2013). Ongoing evaluation and researcher self-reflection are considered essential given the frequently sensitive research content and emergent nature of relationships with communities (Banks et al. 2013).

Researching in communities with the aim of empowering people through power sharing processes can attend to social inequalities and is a guiding principle of the CBPR approach. The ideal is one in which partnerships are formed between community members, organizational representatives, and academic researchers, in which all members of the partnership participate fully and share equal control in decision-making (Minkler and Wallerstein 2008). Although there is merit in this endeavor, it can be difficult to redistribute power in CBPR to achieve an equal power base because researchers continue to be perceived as traditional power holders by community partners (Wallerstein 1999).

CBPR researchers are concerned with achieving ethical conduct of research with collectivities in addition to individuals. Ethics review processes are important, however, many research ethics guidelines are based on the moral individualism of the biomedical model and concerns about collectivities are usually only considered in terms of impacts on individuals (Campbell-Page and Shaw-Ridley 2013). Research proposals are generally evaluated by ethics committees prior to initiation of the research rendering the process misaligned to the emergent nature of CBPR (Guillemin and Gillam 2004; Lofman et al. 2004; Campbell-Page and Shaw-Ridley 2013; Wilson et al. 2017). Therefore, ethical challenges can arise in CBPR, from the conflict between the complex, social, and emergent nature of researching with communities and the operationalization and moral individualism of ethics review mechanisms (Banks et al. 2013). There is potential for unintentional harm where researchers attempt to apply requirements of misaligned models to complex social environments (Flicker et al. 2007).

9 Conclusion and Future Directions

CBPR is an overarching term for a range of collaborative research approaches – centered on community participation. CBPR is an equitable, partnership-based approach to research for social justice and health equity. Researchers using CBPR aim to address inequality by empowering communities to find solutions to their

community problems. Community members are involved in decision-making throughout the phases of CBPR from selecting research questions to dissemination of results. CBPR is translational, with research findings leading to action in the community for community capacity building and health and well-being benefit. The relational nature of CBPR and its emancipatory goals are, however, thought to be at odds with the biomedical model that underpins current research ethics review practice.

In this chapter, the reader has been introduced to key features of CBPR, the phases in its operationalization, and potential challenges for consideration by researchers wishing to use this approach in future health research. As the field of CBPR continues to develop in response to institutional, community, and researcher understanding, it is important that the benefits and the challenges of CBPR for all involved remain prime considerations in research dialogue. Researchers seeking to achieve health equity and social justice will need to work more with communities in trying to solve health and social problems as global developments affect a growing number of people. CBPR offers a useful path forward for researchers responding to these pressing challenges.

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Grounded Theory Methodology: Principles and Practices

18

Linda Liska Belgrave and Kapriskie Seide

Contents

1	Introduction	300
2	A Brief Word on Paradigms	301
3	GTM: How We Do What We Do	302
3.1	Collecting/Constructing Data Simultaneously with Data Analysis	303
3.2	Coding Data (at Multiple Levels), Constant Comparison, and Writing Memos	303
3.3	Theoretical Sampling and Integration of Categories into a Theoretical Framework	306
4	Constructivist/Constructionist GTM and Culture	307
5	Applications of GTM in Health Social Science	308
5.1	Glaser's Objectivist/Realist/Positivist GTM	308
5.2	Strauss and Corbin's Postpositivist/Realist/Interpretive GTM	309
5.3	Charmaz's and Bryant's Constructivist/Interpretive GTM	311
5.4	Clarke's Interpretive/Constructionist/Situationist GTM	312
5.5	Mixing GTM Approaches	313
6	Conclusions and Future Directions	314
	References	315

Abstract

Since Barney Glaser and Anselm Strauss' (The discovery of grounded theory: strategies for qualitative research. New York: Adline De Gruyter, 1967) publication of their groundbreaking book, *The Discovery of Grounded Theory*, grounded theory methodology (GTM) has been an integral part of health social science. GTM allows for the systematic collection and analysis of qualitative data to inductively develop middle-range theories to make sense of people's actions and experiences in the social world. Since its introduction, grounded theorists working from diverse research paradigms have expanded the methodology and

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299

developed alternative approaches to GTM. As a result, GTM permeates multiple disciplines and offers a wide diversity of variants in its application. The availability of many options can, at times, lead to confusion and misconceptions, particularly among novice users of the methodology. Consequently, in this book chapter, we aim to acquaint readers with this qualitative methodology. More specifically, we sort through five major developments in GTM and review key elements, from data collection through writing. Finally, we review published research reflecting these methods, to illustrate their application. We also note the value of GTM for elucidating components of culture that might otherwise remain hidden.

Keywords

Grounded theory methodology · Qualitative research · Culture · Paradigms · Constructivist research · Objectivist research · Realist research · Situational mapping

1 Introduction

Grounded theory methodology (GTM) is a powerful approach to inductively generating theory using qualitative data. In fact, Glaser (1978, p. 2) tells us that “grounded theory is based on the systematic generating of theory from data.” That said, GTM is sometimes used for other goals, for instance, when it is part of mixed methods research (Bryant 2002; Charmaz and Belgrave 2012; Belgrave and Seide *forthcoming*). Barney G. Glaser and Anselm L. Strauss introduced this elegant method in their groundbreaking book, *The Discovery of Grounded Theory* (1967). Since then, it has become possibly the most widely used methodology in qualitative research. GTM has spread across a wide range of fields, extending from sociology and nursing to informatics and engineering, while remaining especially valued in social scientific pursuits of theory regarding health and health care, possibly because it began there, with Glaser and Strauss’ *Awareness of Dying* (1965), their study of death and dying in the hospital setting. Because the term “grounded theory” is used to refer to both the methodology and the product of its use – the theory – we use GTM here, for clarity.

GTM has grown dramatically since the publication of *Discovery*, with more explication and diversity of approach. This diversity includes differences over key features (e.g., Charmaz 1995, 2014; Corbin and Strauss 2015) whether it is a complete methodology or primarily a guide to analysis (Nagel et al. 2015) and, of course, paradigm. At times, the field can seem a bit overwhelming, even turbulent (Bryant and Charmaz 2007a), particularly to novice users of the methodology (Belgrave and Seide *forthcoming*). Here, we review the key elements of the methodology, from data collection through writing, sorting through the major developments in GTM. We give particular attention to (1) Glaser and Strauss’s objective/realist approach, (2) Glaser’s objectivist/realist/positivist work, (3) Strauss and Corbin’s postpositivist/realist/interpretive explication of GTM, (4) Charmaz’s and Bryant’s individual but closely related constructivist/interpretive presentations, and

(5) Clarke's interpretive/constructionist/situationist extension of GTM. Finally, we review published research reflecting these methods, to illustrate their application. We note the value of GTM for elucidating components of culture that might otherwise remain hidden. Our goal is to clarify the options available, so those wanting to use GTM can select the approach that best suits their needs. We appreciate our diversity as a richness of possibilities to be celebrated (see Stern 2007; Clarke 2009; Wertz et al. 2011, for similar approaches).

2 A Brief Word on Paradigms

Distinctions between various approaches to GTM flow from differences in paradigms, which are often unmarked by authors. While "the paradigm wars" might be over, and researchers can take a pragmatist approach to paradigm (Cresswell 2009), it is valuable to examine one's underlying assumptions about what constitutes knowledge, how best to generate it, and the assumptions of the specific methods one chooses in order to reach denser, more meaningful analyses (Fielding 2008). Paradigms have methodological implications (Denzin and Giardina 2009), and researchers will be most satisfied when they work within a paradigm that matches their own. We address paradigm briefly as a guide, rather than advocacy (but see Culture below).

Kathy Charmaz (2000, 2009; Charmaz and Belgrave 2012) differentiates three main approaches to GTM, based on paradigm, postpositivist, objectivist, and constructivist, with some authors moving between paradigms over time. While following her distinctions, we use slightly different labels, reflecting how multiple authors have referred to these approaches and how authors refer to themselves, as well as to recognize that some readers might follow realist assumptions without buying into those of objectivism and vice versa (Belgrave and Seide forthcoming). GTM began in the objectivist vein, so that early explications, such as *Discovery* (Glaser and Strauss 1967) and *Theoretical Sensitivity* (Glaser 1978), provide researchers a methodology to help them uncover a knowable, real social world. They urge those using the method to be neutral and objective. Postpositivism entered the field with Strauss and Corbin's *Basics of Qualitative Research* (1990), in which the authors continue the earlier objectivist assumptions but add detailed techniques to use in analyzing data. This approach began as more prescriptive and procedural than the original, losing the earlier emergent nature of analysis (Charmaz and Belgrave 2012). In later editions of this book, Corbin provides a more interpretive approach (Charmaz and Belgrave 2012; Corbin and Strauss 2015), so that her work as a whole has been interpreted from postpositivist to constructivist (Belgrave and Seide forthcoming). Constructivist GTM (CGTM) is a newer member of the family, developed primarily by Kathy Charmaz and Antony Bryant (see Bryant 2002, 2017; Charmaz 2000, 2006, 2007, 2014; Bryant and Charmaz 2007a, b). Using constructivist GTM, researchers recognize the existence of multiple realities, treat data as mutually constructed between themselves and participants, and see their analyses as constructions of reality. This is an explicitly interpretive approach.

Situational analysis (Clarke 2009, 2015; Clarke and Friesen 2007) extends this approach in a postmodern direction, with an emphasis on situations.

3 GTM: How We Do What We Do

Health social science researchers in the various GTM traditions differ in many ways. Some seek theoretical goals while others are more interested in applied work. Some follow realist/objectivist paradigms; others do interpretive/constructivist work. Certainly, health social science researchers bring a variety of data collection methods to their efforts. Despite this, there is a core of practices common to this diverse family. However, different authors specify different cores. Charmaz (2014, p. 15) lists the most commonly used by those claiming grounded theory as simultaneous, iterative data collection and analysis, analysis of actions and processes, use of comparative methods, and developing abstract conceptual categories through systematic data analysis, though full GTM also includes theoretical sampling, emphasis on theory over description, and more. Corbin and Strauss (2015) do not provide a list, per se, but include an inductive approach to ground the theory in data, constant comparative methodology, coding data and grouping similar codes into categories or themes, developing category properties and dimensions, and integrating all of this around a core category to structure one's theory. Bryant (2017) discusses multiple views of the core, arriving at a list combining characteristics and process of GTM. He argues that GTM is systematic, inductive, and comparative, it involves persistent interaction and constant involvement and is iterative and used to develop theory, and that GTM includes coding, sampling, and being open (to all possible theoretical explanations). In an effort to address all of this in limited space, we discuss the heart of GTM as Sects. 3.1, 3.2, and 3.3. Ideally, we would discuss all of these simultaneously, because we do them iteratively and concurrently, so discussion of any one requires reference to the others. However, that is not possible. We note that sometimes, research being what it is, practitioners fluctuate on some aspects of these, as well, particularly the simultaneity of data collection and analysis (see Ahmad et al. 2006; Beard et al. 2009; Bryant 2017). We present an overview of the methods used by practitioners of the key approaches. For more detail, we refer readers to the classic and recent editions of basic texts for each, including Glaser and Strauss (1967), Glaser (1978), Clark (2009), Charmaz (2014), Corbin and Strauss (2015) and Bryant (2017). Many of these provide examples that show one, concretely, what to do. Additionally, Wertz et al. (2011) and Creswell and Poth (2018) compare GTM to other qualitative methodologies, placing GTM in context. Belgrave and Seide (forthcoming) directly compare coding strategies between various GTM approaches. Finally, we write of methods in the third person plural, reflecting our view of GTM practitioners as members of a large, inclusive family.

3.1 Collecting/Constructing Data Simultaneously with Data Analysis

Although interview and observational data might be the types most typically seen in our work, GTM does not call for a specific form of data, and practitioners use a wide variety of strategies to gather theirs, including both individual and focus group interviews, document collection, observations, mixed methods, and more (Charmaz and Belgrave 2012; Corbin and Strauss 2015; see also ► Chaps. 4, “The Nature of Mixed Methods Research,” ► 29, “Unobtrusive Methods,” and ► 40, “The Use of Mixed Methods in Research”). Below, we refer to interviews, expecting readers to interpret this to include multiple forms of data. Whether we see ourselves as collecting or constructing data jointly with participants depends on the paradigm we follow. This matters more for how we view our work than for what, concretely, we do. Regardless, when using GTM, we start analyzing with the first data we have at hand, typically with some form of coding (see below), thus launching an iterative process, and we use our analysis to inform our ongoing data collection/construction, particularly via theoretical sampling, which in turn aids in explicating categories and integrating them into a theoretical framework.

3.2 Coding Data (at Multiple Levels), Constant Comparison, and Writing Memos

Coding is the most fundamental step in GTM analysis, inseparable from other steps (Glaser and Strauss 1967; Charmaz 2014; Corbin and Strauss 2015; Bryant 2017; Belgrave and Seide forthcoming). Glaser and Strauss (1967) make clear the importance of constant comparison by devoting an entire chapter to it in *Discovery*. In fact, they merely mention coding in this chapter, as they present an emergent, rather than procedural, methodology. At its most basic, coding is a process of attaching conceptual labels to data, labels that capture what the relevant data are about. Although codes are labels, coding is more than labeling. At every level, coding is conceptual; it is analysis. All major approaches to GTM contain multiple, sequentially more abstract, levels of coding. Following these stages, we begin by fracturing or taking apart the data and move toward reintegrating them into a theoretical framework. Clarke’s (2009, 2015) situational analysis (SA), an extension of GTM, uses mapping, rather than coding, per se, as this approach shifts the focus to collective action. As with coding in more conventional GTM, mapping in SA begins with fracturing the data. We organize the following discussion using Charmaz’ constructivist coding strategy (2006, 2014) while noting the schemes of others. Some authors provide tools to help move analysis along productively, which we also note (see Table 1).

Whether we see ourselves as uncovering an existing social reality or working with our participants to co-construct an understanding of social life, we do the same thing for our first coding step. In *initial coding* (parallel to Glaser’s and Corbin and Strauss’ *open coding*), we stick close to the data, attaching labels to segments of data

Table 1 Five major approaches to coding

	Glaser and Strauss	Glaser	Strauss and Corbin	Charmaz and Bryant	Clarke
Research paradigm	Objectivist	Objectivist	Objectivist	Constructivist	Interpretive situationist, constructionist
	Realist	Realist	Realist ^a	Interpretivist	
		Positivist			
Approach to coding	Comparisons:	Substantive coding:	Open coding	Initial coding	Open coding ^d
	Incidents	Open coding	Axial coding	Open coding	Axial coding ^d
	Incidents to properties	Selective coding	Selective coding	Focused coding	Situational mapping
	Delimit theory	Theoretical coding		Varied coding strategies ^b	Social worlds
				Axial coding ^c	Arenas mapping
				Theoretical coding ^c	Positional mapping
Analytic tools		Coding families	Conditional matrix	Coding families ^c	
Early coding	Incidents	Line by line	Paragraph by paragraph	Line by line	Word by word
			Phrase by phrase	Incident by incident	Segment by segment
			Line by line	Word by word	
			Micro coding (specific strategic words)		

Table reprinted from Belgrave and Seide ([Forthcoming](#))

^aInterpreted variously, from postpositivist to constructivist

^bBryant provides varied examples of strategies for moving forward from open codes

^cDiscussed by both: neither advocated nor discouraged

^dOverview presented, not instructional per se

to capture what is going on in those segments. Segments of data might be single words, phrases, lines, paragraphs, or incidents, depending on the approach we are using, the nature of our data and our research goals. We fracture the data in order to be able to see what is happening – the trees unobscured by the forest. Charmaz (2006, 2014) and Bryant (2017) strongly encourage coding with gerunds; these active verbs help us to focus on processes. The key in initial coding is to remain open to possibilities. In fact, Glaser and Strauss (1967) and Glaser (1978) recommend attaching multiple codes to segments of data. Whether we use in vivo codes (words used by participants) or other labels, these are abstractions. With the coding of our first data, we write our first memo(s). Memos are notes we write to ourselves in order to keep track of our analytic thoughts. Early memos tend to be short and simple notes about codes that strike us in some way. These might be codes that seem

significant, unexpected, or simply interesting. They are things we might look for in future data collection/construction or probe for in upcoming interviews. After we code our second interview, we compare it to the first, seeing what is similar, what is new, what is cast slightly differently, and so on. In the third interview, we compare to the first two. These comparisons might suggest new or revised codes (and memos!), as we see codes that somehow “go together.” We create new codes and recode, never losing the early ones, and write new memos. And so it goes, with constant comparison of new to data to earlier data, new codes, recoding, and more memos, always expanding our analytic ideas. Constant comparisons, at varying levels of abstraction, are at the heart of GTM.

When do we move to the next level of coding? There are no rules, *per se*. As we continue to collect/construct, code, and compare data, we find that some codes appear frequently. Others do not. Some codes appear to be potentially theoretically exciting and others less so. Our memos become longer and tell more of a story. These are signs that we might begin to think about moving to the next coding level and focusing our data collection/construction. The reason the previous sentence is phrased cautiously is that it can be tempting to leap ahead prematurely, something Glaser (1978) warns us to avoid. We want to collect/construct enough data to have a chance to see/find similarities, differences, theoretically interesting codes, and the like. At the same time, one of the strengths of GTM is that it helps us to focus our data collection/construction (Charmaz 2014) so that we do not spin our wheels collecting/constructing reams of redundant data that add nothing new to our theoretical analysis. Moving to the next level of coding requires taking a risk, but it is a risk that can be undone.

With *focused coding*, we move to higher levels of abstraction, combine codes into categories, and begin to **integrate categories into theoretical frameworks**. Now, we compare our *initial codes* to each other. We want to select codes that appear the most often, codes that carry much analytic power, and codes that pull together many *initial codes*. We do this in a way that helps us to construct *focused codes*, categories, and their characteristics. Charmaz (2014) suggests that we ask questions such as “Which of these codes best account for the data? What do your comparisons between codes indicate? Do your focused codes reveal gaps in the data? What kinds of theoretical categories do these codes indicate?” (2014, pp. 140–141 and 144). Gaps, characteristics of *focused codes* that are not “fleshed out,” or things that we would expect to see, but do not, lead us to theoretical sampling (see below).

For Glaser (1978), the second step is *selective coding*. Here, we focus on one “core variable” and other “variables” that appear to be related to it. This “core variable” is similar to a *focused code*, in that it guides ongoing data collection and theoretical sampling. It is different in that Glaser’s “variables” tap reality. Finally, using Glaser’s scheme, we turn to *theoretical coding*, integrating our fractured codes by conceptualizing relationships among our substantive codes (a grouping that combines *open* and *selective codes*). Glaser provides coding families (1978) and conceptual schemes intended to add precision and clarity to our higher-level abstractions. These can be helpful but risky if we find ourselves forcing these onto our data or using them uncritically, as some contain assumptions that we might not want to

include in our eventual theory (Charmaz 2014). Corbin and Strauss (2015) offer axial coding, a paradigm to use in teasing out properties and dimensions of categories and bring our fractured data back together by relating categories to subcategories, at a higher level of abstraction. Some will find this helpful, though if it is applied mechanically, it can be limiting (Charmaz 2006, 2014). In earlier versions of their work (e.g., 1990), Strauss and Corbin next had us move to *selective coding*, which is similar to Glaser's. It is also similar to their *axial coding*, only at a higher level of abstraction, but in the 2015 edition, this is subsumed as part of *theoretical integration*.

We discuss situational mapping separately because it is an extension of conventional approaches to GTM and, therefore, looks rather different. Clarke (2009, 2015) lays out three types of mapping, *situational*, *social worlds/arena*, and *positional*. These seem to parallel some of the coding steps outlined above, except that we draw social maps. In *situational* mapping, we lay out "the major human, non-human, discursive, and other elements in the research situation of inquiry and provoke analysis of relations among them" (Clarke 2009, p. 210). We do this in two steps. The first, *messy mapping*, is similar to *initial coding*, in that our goal is to capture complexity. We make working maps, open to change. Clarke provides possible categories (e.g., individual human elements, collective human elements, and spatial elements) to use for the second step of *ordered mapping*. These are analogous to the tools provided by Glaser (1978) and Corbin and Strauss (2015), intended to nudge our thinking but not to be forced on our data. *Social worlds/arena mapping* is intended for meso-level analysis. Here, we attend to social organizational, institutional, and discursive dimensions of the situation. Finally, with *positional mapping*, we focus on "major positions taken, and *not* taken, in the data," whether these are taken collectively or individually (Clarke 2009, p. 210). In this step, we move between levels of analysis, from individual to organizational. We believe situational mapping has tremendous potential for health social science, particularly as healthcare is provided in situations and organizations, all impacted by decisions made at high levels of organizations and political-economic systems.

Back to those memos – we have been writing and elaborating memos throughout this process. In our memos, if we include the relevant segment of data that gives rise to an *initial code* or is tied to a *focused code*, our analysis is physically and visibly linked to our data. This keeps us grounded in our data. As we finalize our inquiry, we see that not only have our memos helped us keep track of our ongoing analysis but much of our writing is done! Now we can clean the memos up and incorporate them into papers reporting our research. If we have included quotes from our data in our memos, we have examples at our fingertips.

3.3 Theoretical Sampling and Integration of Categories into a Theoretical Framework

As we work at advanced levels of coding, integrating categories into a theoretical framework, we typically find puzzles. Perhaps we cannot figure out why a category

does not have a characteristic we think it should have, logically, or we see a glimpse of how two categories fit together, but a piece of the picture seems to be missing.

All conventional approaches to GTM call for theoretical sampling, with authors generally devoting significant space to explaining it (Glaser and Strauss 1967; Glaser 1978; Charmaz 2014; Corbin and Straus 2015); it is also raised by Clarke (2015) in reference to situational mapping. And yet, the practice is often misunderstood. We draw primarily on Charmaz (2014), who provides perhaps the clearest discussion of this aspect of integrating analysis and data collection/construction. Our goals in theoretical sampling are not to achieve some sort of representative sample, only sometimes to seek negative cases, and decidedly not to document consistent empirical patterns. Rather, we use theoretical sampling to collect/construct data to refine and elaborate our emergent *theoretical* categories, tease out their properties and ranges, and illuminate relationships between them. As we work our focused (and/or other levels of coding beyond the initial), we use abductive reasoning. That is, we make “inferential leap[s] to consider all possible theoretical explanations for [surprising or puzzling] data” (Charmaz 2014, p. 201). Then we go back to our data or collect/construct new data to use in trying out these possible explanation(s). The keys here are that we imagine theoretical explanations for our data and use data to examine these. We might already have the relevant data and simply need to look at it through a new lens. We might go back to some participants and ask them new questions. Or we might recruit new participants whose experiences or stories might hold the solution to what puzzles us. Whichever we need to do, we use our theoretical insights and reasoning to guide us in seeking new or relevant existing data. We use our theoretical sensitivity to generate insights, but ideas, categories, and concepts must earn their way into the theory (Glaser 1979; Charmaz 2014; Clarke et al. 2015).

4 Constructivist/Constructionist GTM and Culture

Culture is critically important in social scientific research in health, health beliefs, health practices, and the like (Quah 2007; Liamputtong 2018). Here, we do not use the term culture as a euphemism for ethnicity or language, much less race, though we know the literature is replete with such work. Ethnicity and race themselves, though often taken for granted as adequately summarized with labels referring to national origin, continent of origin, or language (of self or ancestors), are socially constructed, changeable, and quite complex. For instance, Linda (first author) left Cleveland, Ohio, as an ethnic, non-Hispanic white. Ethnically, she was variously assumed to be Jewish or unspecified Eastern European, while she identified as Slovak. She arrived in Miami as an Anglo, period, though one of her students frequently tells her “but you’re not white,” intended and taken as a compliment. Add to this that she grew up solidly working class but now finds herself identified by others as middle class. Pile on religion, and the messiness of culture, begins to become obvious. By culture, we refer to “characteristics of a group’s or community’s way of life” (Quah 2007) that are relevant to health issues, including such things as

values; shared meanings of health and illness, life, and death; traditions, customs, and habits; understandings of power and status relationships; lifestyles; and, yes, sometimes religion and language (adapted from Quah 2007; see also Liamputtong 2018). Moreover, we recognize culture as intersectional with race, ethnicity, class, gender, sexuality, and more. Kapriskie used CGMT to explore the impact of a cholera epidemic on the everyday lives of Haitians in view of a divide between public health experts and the population regarding the effectiveness of implemented local policies (Seide 2016). Although she was born in Haiti, ongoing cultural changes required some personal and methodological adjustments. Through field-work observations and reflexivity, she (re)familiarized herself with historical and evolving stratification dynamics based on social class and skin color that permeate everyday life. With memo writing, she continuously confronted her positionality as a researcher. In Haiti, the legitimacy of her role as a scholar along with the validity of her data reposed on recognizing culturally embedded factors that one could take for granted. Examples include, but are not limited to, the status of her advisor and that of her parents. Some participants interpreted having a white research advisor as respectable, while her parents (who are bridges in large social networks) facilitated snowball sampling and authenticated her Haitian roots for some natives (see Ulysse (2006) on the othering of emigrants by native Haitians). Her self-presentation and her degree of familiarity with local sites were also relevant to managing the field-work. Occasionally, the way she dressed determined her entry in some social circles. Because of the spatial distribution of the disease, knowing the city's "hotspots" became a *sine qua non* to establishing rapport with participants during interviews. Each form of GTM has methodological and theoretical implications for the recognition of similar subtleties in health research.

5 Applications of GTM in Health Social Science

Having laid out the key elements of GTM, we now turn to a few studies to show the diverse application of GTM in research pertinent to health sciences. What we present here is by no means meant to be exhaustive; rather, we offer a few illustrations to complement our discussion of the GTM variants. We manually reviewed different articles' methodologies and chose those that fit with our thematic focus. Accordingly, we selected eight (8) articles drawn from multiple disciplines – each applying a variant of GTM to answer key research questions. This multiplicity speaks to the utility of the methodology to the expansion of theory and – in some cases – the explanation of components of culture.

5.1 Glaser's Objectivist/Realist/Positivist GTM

Larsson et al. (2007) explored the experiences of patients who are actively involved in their own care and their expectations of this process. Patient participation in healthcare decision-making is an integral part of the quality of services, the

improvement of health outcomes, and the autonomy of patients. The team organized focus group interviews with participants recruited from four local hospitals in Sweden. All interviews were recorded and transcribed verbatim. To analyze the data, they used the constant comparative method. In their methodology, they organized their data into codes. Substantive codes conceptualized participants' description of patient participation in nursing care. The method of this study reflects the Glaserian research paradigm in several ways: the researchers conceptualized relationships among substantive codes, they used coding families in the theoretical coding stage, and they worked with the concept-indicator model, as the data (description of event, experiences, and actions from the interviews) were indicators of main concepts. The researchers generated a core category out of four interrelated categories that outlined the nurse-patient interaction, which involves series of structural and individual-level factors. For example, *Rights* is one of the four categories that emerged from data about patients' expectations of nurses' roles. According to this category, patients expect nurses to protect their rights. This need impinges on the quality of the patient-nurse interaction and is an essential part of the patient participation in nursing care. Overall, findings pointed to new discoveries and were aligned with the existing literature. Brown (2006) followed the same approach but differed in two ways. First, she explicitly drew from Glaser and Strauss's approach while providing details on her methodology. Second, she generated the shame resilience theory to explain women's experiences with the emotion of shame – a mental and public health issue for social workers. Data included more than 200 individual interviews. Just like Larsson and colleagues, Brown sought to conceptualize shame and outline its underlying mechanism, its impacts on women, and the ways in which it is managed. In accordance with Glaser's approach, both studies focused on conceptualizing and explaining patterns to clarify concepts. In the case of Brown (2006), the theory generated accounts for a phenomenon that concerns participants.

While neither of these two studies examined culture per se, they underlined the significance of participants' perspectives within specific contexts. In alignment with the Glaserian approach, there is a (artificial) boundary between researchers and participants. In this position, the studied phenomena are embedded in a reality *sui generis* and can be uncovered with the use of GTM as a methodological tool. Consequently, in the first study, the meaning of patient participation in nursing care is *revealed* from a patient point of view. In the second study, interviews were conducted to theoretically *determine* several aspects of women's experiences with shame.

5.2 Strauss and Corbin's Postpositivist/Realist/Interpretive GTM

Bateman et al. (2013) heavily drew from this approach while explicitly disclosing their epistemological stance, said to be parallel to that of Corbin. They created a theoretical model that describes and predicts how undergraduate medical students learn from virtual patients (VPs) and the mechanism of this human-machine

interaction in light of a paucity of research on the matter. VPs are game-based learning tools and interactive computer simulations of real-life clinical cases used in healthcare education (Kononowicz et al. 2015). For this research, 48 students from one medical school completed two VP cases that the researchers designed. Subsequently, participants evaluated the tool and partook in focus group discussions. The focus group interviews were digitally recorded, transcribed, and coded to develop preliminary categories. The researchers sought to validate their interpretations of the data by constantly comparing them. As a team, they coded their data line by line with in vivo codes and then advanced to axial coding. They used emergent themes to guide their sampling method. In the selective coding stage, they established a central core category, labeled “learning from the VP,” that is connected to other categories. For example, they found that learning from VP cases depends on the way VPs are constructed (how realistic, clear, and well formatted the fictitious cases used in the VPs are), the characteristics of the student and the educational institution, the experience of the student with technology, and the outcomes of this human-machine interaction. In this study, the researchers were attentive to the ways in which students’ subjective experiences could be abstracted into theoretical statements about the causal relationship between learners and technology, using group interviews and observations. In addition to acknowledging the potential biases in their inquiries, the investigators convened a research team composed of different health experts and implicated them in the theory-building process in an iterative fashion. Lindsay et al. (2011) also followed this variant of GTM to *uncover* the experience of men living with chronic gout – a highly treatable, yet undermanaged and poorly diagnosed, illness worldwide. They identified three major themes linked to the experience of gout. Just like Bateman and his colleagues, this study iteratively engaged a group of professionals in the research process to analyze and validate the themes that emerged from the data. Based on their interpretive leaning, these researchers relied on experts and participants alike to define the phenomena. For example, the second set of researchers, while consulting their team of experts, found that men suffering with gout might experience wide-ranging degrees of pain with disastrous effects on their social life, their social roles, and their self-identity. Both studies diverge on one key aspect, the former explicitly indicating their theoretical stance. Bateman and his colleague (2013, p. 596) “acknowledge[d] the positivist origins of grounded theory, whilst recognizing and valuing constructivism and reflexivity in the context of [their] pragmatist theoretical orientation and training.” For the latter, one can deduce their realist paradigm from their methodology.

In these studies, the notion of culture is not stressed. Still, the analyses hint at a consideration of certain cultural characteristics. In the first study, the researchers analyzed the effectiveness of a learning tool for students within an institutional context that has its own culture. Since they designed the VP cases, they recognized that individuals construct medical knowledge within the social institution. In the second study, the investigators examined a health issue among men in South Auckland, New Zealand. From a sociological perspective, we argue that lay perspectives and gender are culturally relevant. In the latter study, for instance, the gender used in the analysis is subject to specific social expectations, mode of

socialization, and cultural scripts in Auckland. In both studies, researchers, more or less, treat the examined phenomena as things that exist in an independent reality, outside of the researcher and the participants' conceptual scheme. Meanwhile, they also accept the difference between lay and experts' perspectives in their methodology. To illustrate the centrality of culture in the application of this form of GTM, we refer to Aita and Kai's (2010) GT study of life-sustaining treatment (LST) practices among healthcare professionals in Japan. They applied Strauss and Corbin's GTM in their analysis and followed the same steps as the two studies reviewed in this section. Meanwhile, Aita and Kai's desire to examine these practices was motivated by the cultural irrelevance of Anglo-American guidelines on withholding and withdrawing life-sustaining treatments (LST). This study disputed the implementation of these Western medical protocols within a Japanese context by outlining the experiences, attitudes, and perceptions of 35 Japanese physicians regarding withdrawal of mechanical ventilation and other LST. Differences in cultural beliefs and attitudes vis-à-vis withdrawal of artificial devices from dying patients pointed to the danger of globalizing certain Western medical practices and the heterogeneous conceptualization of ethics. GTM allowed for the systematic identification of barriers hindering the implementation of these guidelines for Japanese physicians working at emergency and critical care facilities in that country.

5.3 Charmaz's and Bryant's Constructivist/Interpretive GTM

Poteat et al. (2013) drew from the work of Charmaz (2006) to explore the experience of transgender patients with discrimination in healthcare access and utilization. The disentanglement of this phenomenon is essential to addressing health disparities for transgender people. The researchers analyzed typed field notes and 67 individual in-depth interview transcripts (with 55 transgender patients and 12 healthcare providers working in institutions that serve transgender patients). This study also included two "community advisory boards" composed of transgender individuals throughout the research process to "ground" the study in the community interest (23). This partnership-like approach resembles community-based participatory research (CBPR) but also respects CGTM's principle of viewing the world from the standpoint of their participants (see also ► Chap. 17, "Community-Based Participatory Action Research"). The research report emphasizes reflexivity and highlights the role of the researchers as co-authors in the research process – a key characteristic of the constructivist approach. The authors critically examined their construction of the research process as they explored how participants constructed their experiences. The interviewers wrote reflexive notes as well as general field notes after each interview. Further, one of them kept a reflexive journal to differentiate her views from those of participants – treating the research process itself as a social construction and accepting her bias and positionality as a researcher. In their analysis, the researchers found that power is a grossly overlooked element in this dyad. At this level, stigma underpins the unbalanced dynamic of power in the asymmetrical relationship between transgender patients and healthcare providers. Unlike the

aforementioned studies, findings *emerged* through an interactive process between researchers and participants. A comparative method was used in all of the studies thus far; however, in this study, the data were not deemed objective. This study supplied an interpretive understanding of stigma in the healthcare provider-patient relationship and was able to highlight the impact of power in this interaction.

The method and strategies adopted from a constructivist approach offered a systematic way of delving into the pervasive practice of patient stigmatization embedded within an institution that has its own sociohistorical and cultural context. Unlike the other studies referenced, Poteat and colleagues paid attention to the nature of the interaction between members of opposing groups. In this inquiry, they studied stigma relationally and conducted a context-rich analysis of healthcare provider-patient relationship. In doing so, they tapped into the active involvement of individuals in constructing meaning from their hierarchical relationship. By placing individuals' agency and social roles in the front stage, the researchers were able to construct the meaning of stigma within a medical clinical context.

5.4 Clarke's Interpretive/Constructionist/Situationist GTM

Erol (2011) examined the medicalization of osteoporosis (OP) in Turkey and followed the situational analysis approach. Specifically, she examined how risk related to postmenopausal osteoporosis is discussed in lay and medical Turkish literatures. She collected ethnographic data, archival data (newspapers and magazines on menopause), 52 individual semi-structured interviews with hospital attendees (31 menopausal patients and 21 doctors), and three group interviews. Like conventional GTM, the analysis begun with fracturing the data and then led to their reintegration into cohesive theoretical framework (Clarke 2009). She also set up different maps (situational, relational, social worlds-arenas) to complement the analysis of the collected data. All interviews were transcribed verbatim and the first round were initially coded. When she finished gathering data, she revised those initial codes and excavated more data to further analytic ideas. Based on her findings, the construction of osteoporosis occurs at different levels. For example, biomedical explanations attributed the risks of developing OP to menopause and deemed it preventable with lifestyle changes – putting the burden solely on the individual. One of these changes entailed wearing modern clothing as opposed to traditional ones to increase women's exposure to the sun. Then, the media disseminated and reinforced these messages. Lastly, they swayed public perceptions and attitudes regarding OP – inducing anxiety among women in some cases. The framing of this health condition as a behavioral problem points to glaring cultural components. First, it depicts the risks of OP as an issue that is rooted in the habitus of women who are accustomed to wearing traditional clothes that cover their whole body. Second, it singles out women's agency (the selection of clothing which is a quintessential cultural behavior) as the primary determinant of OP risks. This established causal link is legitimized, disseminated, and cemented in cultural beliefs about OP. As the researcher underlined, an “embodied modernity is expected of the menopausal Turkish woman

to counterbalance the embodied risk of osteoporosis” (p. 1496). This study outlines numerous structural (the media, the medical institution, the local clinics)- and individual-level factors contributing to the construction of osteoporosis as a gendered issue.

Central to Erol’s study is the examination of discourses around postmenopausal OP in Turkey. The use of Clarke’s approach to GTM enabled Erol to explain the social construction of a health condition in a culture. The researcher collected data from a variety of sources and analytic strategies to conduct a context-rich analysis on the medicalization of the risks of OP and the legitimation of this construct at different levels: macro (society), meso (organizational), and micro (individual). Situational mapping allowed for the elucidation of healthcare practices specific to postmenopausal women at risk of developing OP in Turkey.

5.5 Mixing GTM Approaches

Researchers can combine different approaches to examine a phenomenon from which they may attempt to “discover theory from data” (Glaser and Strauss 1967, p. 1). Schnitzer et al. (2011) used CGTM, Strauss and Corbin’s paradigm model, and situational analysis to examine the decision process of ultra-Orthodox Jewish parents to utilize healthcare services for their children in Antwerp, Belgium. First, they drew from CGTM to analyze the interviews and coded line by line with *in vivo* codes. Then, following Strauss and Corbin’s paradigm model, they defined links between categories and incorporated them into a procedural diagram that illustrates the help-seeking pathways of the parents. They also used three mapping techniques to explore how different people and groups (collectives), situations, contexts, and discourse influence parents’ decision-making.

The application of GTM is not always the same and changes in accordance to research questions and researchers’ theoretical leanings and goals. Unfortunately, not all GTM studies have a transparent and rigorous description of the methodology. This gap is not necessarily a testament to the quality of existing GTM studies. Structural constraints, like page limits in many journals, could affect the level of detail revealed. Nevertheless, we observed an epistemological issue with authors’ confusing grounded theory with other methodologies. This could make the assessment of the form of GTM researchers are using a problematic endeavor. In the studies that we selected, investigators, more or less, use the core analytic tenets of GTM, outline their respective ontology, and use the technical language aligned with their approach. Given all of this, for studies in which the examination of culture is seriously intended, we recommend the use of constructivist/constructionist GTM (CGTM). The recognition by CGTM that meanings, practices, and values are socially constructed, rather than inherent in labels, and that these are changeable parallels the complexities of culture. The reflexivity demanded of the researcher by CGTM makes it ideally suited for deeper looks at culture and how it connects to health and illness; reflexive awareness of the joint construction of research can steer

one toward actively listening to research participants, truly hearing them, and managing what one sees through her or his own cultural lens.

6 Conclusions and Future Directions

Clearly, GTM has much to offer health science researchers and is widely used in this field. There are multiple approaches to GTM, based on differing, often unstated, paradigmatic assumptions. Yet, these share a common core of actual research practices. Charmaz (2006, p. 9) writes: “[R]esearchers can use basic grounded theory guidelines such as coding, memo-writing, and sampling for theory development, and comparative methods are, in many ways, neutral... *how* we use these guidelines is not neutral; nor are the assumptions they bring to our research.” It is best to consider one’s own assumptions, in order to choose the approach best suited to one’s research goals. While one can draw on multiple approaches, using helpful techniques is not clear that one can successfully mix paradigms in a single piece of research (Cresswell 2013, 2018). Moreover, readers will read into one’s work, making assumptions about one’s paradigm (Cresswell 2009, 2018). More troubling to readers, researchers often claim to be using GTM without providing further details, leaving them in a quandary as to what was actually done. With journal space limited, it is difficult to provide much in the way of methodological detail. That said, specifying one’s approach can be helpful. Specifying some methodological detail would be even more helpful.

Culture is often a significant component of health meanings, beliefs, practices, services, and institutions, even when it is not an explicit component of one’s research. It can be valuable to keep culture in mind as a sensitizing concept. This is not to advocate forcing consideration of culture onto one’s data or findings but to recommend that researchers be aware that culture might be a factor in the issue being studied and/or the conduct of one’s research (see Liamputtong 2010).

As indicated in our review of selected studies reflecting the application of GT methods, net of the subdiscipline, epistemologies have major implications for the research process. To account for cultural subtleties in future analyses, health science researchers may find GTM, particularly CGTM, especially useful. This variant of GTM is an alternative to the objectivist GTM which can either be impervious to culture or treat it peripherally. From this viewpoint, CGTM points to a new direction as it is ideally suited for tapping into the impact of culture on the social side of health phenomena. It is also noteworthy that attention to specific cultural practices is valuable for studying issues of social justice in healthcare, as illustrated by the work of Poteat et al. (2013) discussed above.

Regardless of the approach followed or how techniques from different approaches are mixed, GTM involves continual movement between data collection/construction and analysis and between concrete data, memos, and abstractions. This is iterative work; to lose sight of one’s data is to put one’s theory at risk. That said, GTM is a robust methodology, one that can be used to enter and come to understand participants’ worlds. Use it in good health!

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Case Study Research

19

Pota Forrest-Lawrence

Contents

1	Introduction	318
2	What Is Case Study Research?	319
2.1	A Case Study: Definitions	319
2.2	Case Study: Types and Designs	320
3	Why Is It so Misunderstood?: Limitations of Case Study Research	321
4	The Artistry of the Case Study: Advantages of Case Study Research	323
5	A Different Form of Knowledge: The Unshackling	324
5.1	Generalization	324
5.2	Naturalistic Generalizations	326
6	Conclusion and Future Directions	329
	References	330

Abstract

Case study research has been extensively used in numerous disciplines as a way to test and develop theory, add to humanistic understanding and existing experiences, and uncover the intricacies of complex social phenomena. Its usefulness as an exploratory tool makes it a popular methodology to employ among social scientists. This usefulness, however, has, at times, been overshadowed by several misunderstandings of and oversimplifications about the nature of case study research. Although these misunderstandings, such as the inability to confidently make scientific generalizations on the basis of a single case, may be presented as limitations, they should not detract social scientists from using case study research for certain critical research tasks. Used in such a way, case study research

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317

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holds up considerably well to many other social science methodologies and can certainly contribute to the development of knowledge. This chapter examines case study research with emphasis on its “generality,” notably what Stake proposed as “naturalistic generalization,” a proxy process that enables the generalization of findings from a single case. It will interrogate the misunderstanding that case study research cannot effectively contribute to scientific development, by focusing on single-case designs. Single-case designs attempt to understand one particular case in-depth and allow for a richer understanding of the issue under investigation.

Keywords

Case study · Single case · Qualitative research method · Generalizations · Naturalistic generalizations

1 Introduction

Case study research has come to occupy a prominent place in the evolving social science landscape. Focus on this largely qualitative research method has positioned the case study as a popular “go-to” method for researchers. Its flexible approach has allowed for its extensive use in both qualitative and quantitative studies and within a vast range of disciplines including but not limited to political science, law, public health, medicine, business, social science, and education.

The versatility of the case study has positioned it at the forefront of preferred methodological approaches for many researchers. In this way, it can be used in exploratory, explanatory, and evaluation types of research to develop theory and generate and test hypotheses and can embrace varied epistemological orientations. Such features have made the case study quite an attractive research method to employ within the social sciences.

While this attractiveness has increased its popularity, it has also highlighted what some consider its many shortcomings (see Gerring 2006). One such shortcoming is the inability for a case study to make scientific generalizations. These generalizations center on notions of predictability, validity, and causation and are considered by many as the only way in which researchers can understand complex social phenomena. The perception of formal generalization as the only contributor to scientific development ignores the value of other types of generalizations that can effectively contribute to scientific knowledge and progress.

This chapter will commence with an overview of case study research, detailing some of its uses and applications. Following this summary, it then examines why it is so misunderstood as a methodology and then highlights some of its advantages. This then leads to a key focus of the chapter, generalization, by examining the utility of single-case designs as contributing to scientific development via a process proposed by Stake (1978) known as “naturalistic generalization.” The chapter will conclude with a brief discussion about future directions for case study research.

2 What Is Case Study Research?

Reviewing a plethora of material and literature on case study research does little to synthesize the complementing yet, at times, contradictory definitions of a term that has come to mean different things to different disciplines. What we do know is that case study research clearly places cases *not* variables at center stage (Ragin 1992). With this in mind, the attempt here is to offer a broad-strokes overview of case study research.

Some of the earliest documented historical case studies can be traced to the works of ancient Greek writers Herodotus and Thucydides (Elman et al. 2016). Though by far, scientific revolutionist Galileo and his rejection of Aristotle's law of gravity via the process of gravitational force is considered one of the most famous case studies of the last millennium (Flyvberg 2011). Many such "case studies" have subsequently filled the pages of history books, presenting detailed overviews of complex "cases," Graham Allison's methodical case study analysis, one such contemporary example (Allison 1969). Using an explanatory single-case study, Allison examined the 1962 Cuban Missile Crisis in intricate detail. These contributions highlight specific and unique cases and offer insight into both the value of the case study and its many uses and applications.

The use of case studies according to discipline is highlighted by Thomas (2011). Here, Thomas notes that disciplines such as psychology, sociology, and education position the case study in a largely "interpretive frame." Alternatively, disciplines such as politics and business adopt a more neopositivistic epistemological stance by largely identifying variables as cases. This approach, claim Bartlett and Vavrus (2017), views the world via laws centered on cause and effect, where scientific methods prevail. Other disciplines such law and medicine largely highlight novel phenomena. Such different uses of the case study according to a researchers' epistemological stance highlight the diversity and flexibility of the case study.

2.1 A Case Study: Definitions

Such wide-ranging applications, however, do present difficulties in defining a case study (Exworthy & Peckham 2012). A plethora of definitions, explanations, insights, and understandings has made it difficult to provide a single definition of a concept so widely used. This is further compounded by the need to recognize both the researchers' methodological and epistemological stance when conceptualizing a definition of a case study (Bartlett and Vavrus 2017). The following details a number of definitions of a case study and presents ways to understand its meaning and contribution:

- A research method that involves an in-depth understanding and analysis of a case.
- A form of empirical social enquiry that interrogates social phenomena both in detail and in a real-world context (Yin 2014, p. 6).

- A “frame” that “determines the boundaries of information-gathering” (Stoecker 1991, p. 98).
- A framework that centers on answering a specific question relevant to a case (Seawright and Gerring 2008).
- An intensive examination of a single case whose aim is to illuminate a larger set of cases (Gerring 2007, pp. 20, 65).
- Cases can be anything from an event, organization, group, person, and so on. They can influence the development of public policies and practices in a broad range of fields (Duff 2014, p. 234).
- The phenomena studied are done so in their natural surroundings (Swanborn 2010, p. 15).
- Provides a multifaceted way of structuring our understanding of reality.
- Offer an explanation that holistically captures the dynamics of a period in time and of a certain social unit (Mills et al. 2010, p. 17).
- Its chameleon-like epistemological qualities allows it to embrace many different orientations (Yin 2014, p. 17).
- Can uncover patterns, establish meanings, reach conclusions, and build theory (Stake 1995, p. 67).
- Can examine causal mechanisms, test theoretical predictions specific to general models, and detail features about a specific case (Gerring 2007, p. 5).
- Allows for an intimate understanding of a phenomenon under investigation of which “the case is exemplar” (Duff 2014, pp. 236–237).
- Case study research is “not a methodological choice but a choice of what is to be studied” (Stake 2005, p. 443).

While these definitions offer some insight into the case study and, by doing so, highlight qualities that present it as an attractive research approach, it is still considered by some to exist and survive in a “curious methodological limbo” (Gerring 2007, p. 7). While this may limit its attractiveness, it still thrives because of its utility and its focus on qualitative research methods as methodological rivals to the once dominant quantitative and “positivist” models of causal explanations (Gerring 2007; see also ► Chap. 9, “Positivism and Realism”).

2.2 Case Study: Types and Designs

Researchers typically employ a descriptive, exploratory, or explanatory case study to examine and understand the phenomenon under investigation. A descriptive case study describes the phenomenon in its context. Whyte (1955) used a descriptive case study to examine an Italian-influenced US neighborhood. Alternatively, an exploratory case study aids in the development of theories and hypotheses, whereas an explanatory case study explains how events transpire over time. It can also examine cause and effect relationships. As highlighted earlier, Allison (1969), for example, employed an explanatory single-case study to examine the 1962 Cuban Missile Crisis.

2.2.1 Multiple-Case Designs

A case study can either comprise a multiple-case or single-case design. A multiple-case design is typically selected to provide a better understanding about a collection of cases, as well as explore, test, and build theory. Stake (2006) notes that a multiple-case study examines how the subject of interest operates within different settings and within different contexts. Yeh and Hedgespeth (1995), for example, employed a comparative multiple-case study of 15 families of adolescents to examine the relationship between particular family factors and alcohol/drug abuse.

2.2.2 Single-Case Designs

A single-case design is appropriate should a researcher want to understand and examine one social phenomenon in detail (Merriam 1988). This design type also allows for an elaboration of quite complex characteristics of a single case (Duff 2014). Similarly, Stake (2005, p. 445) notes that the single-case design attempts to understand one particular case in-depth rather than what is mostly “. . . true of the many.” Skar and Prellwitz (2008) used a single-case to describe how a child diagnosed with obesity understood his involvement in play activities. This method allowed them to provide a deeper understanding of the issue.

According to both interpretivists and realists, a single case is able to provide different accounts of causation, clarify theoretical relationships in a certain setting that may appear obscure, and construct theory (Mills et al. 2010). They can also offer a useful understanding and intimate knowledge of the particulars of a singular case such as a school, locality, type of food, and so on. This, according to Stake (1978, p. 6), showcases how the “truth lies in particulars.”

While Stake (1995) claims that there is much one can learn that is considered general from a single case, single-case design studies are generally perceived as a poor basis for scientific generalization and, therefore, weaker than other types of research designs. This perception, however, neglects to emphasize the uniqueness of the case study and its potential as a valuable and informative research methodology.

3 Why Is It so Misunderstood?: Limitations of Case Study Research

While its varied uses may be one of its more appealing features, the case study is simultaneously criticized for its lack of rigor and representativeness (considered weaker with respect to external validity as it comprises a small number of cases) (Gerring 2007) and its inability to generalize, particularly from a single case (Simons 1986). Hamel (1993) highlights how these limitations are presented as fundamental flaws, particularly if considered in the context of the collection, construction, and analysis of empirical material. As a result, the case study has been “disregarded as a methodology” and relegated to something unscientific notably by proponents of causality via quantitative approaches, who consider this approach as the only way one can add to scientific knowledge (Flyvberg 2011).

Presented as the “weak sibling” of the social sciences methods, the case study has been further criticized as something “mere,” “biased,” “subjective” (though this may not necessarily be considered a weakness), and “non-generalizable” with “weak empirical leverage” that is highly “suspect” (Yin 1984; Gerring 2006, pp. 6–7). Such constructions suggest that generalizations cannot be made via case studies because they defy the laws and methods of physics, where *closed systems* are only used, meaning these systems are isolated from their environment (Bertalanffy 1973, cited in Patton and Appelbaum 2003). What Stake (1995) demonstrates, however, is that a case is both an open and an integrated system, where the rules of “closed” systems of the casual sciences *do not apply*. This is clearly something either ignored or overlooked by those who openly criticize the case study as unable to contribute to scientific knowledge and an understanding of the world.

This negative construction of the case study positions it as subordinate to natural sciences methods and secondary to studies that typically comprise large samples. Such a perception stems from a normative (empiricist) view of research – *what it ought to be, how it ought to be conducted, and what it ought to do*. This, according to Simons (1986), assumes a rather specific polarity, one considered quite inflexible.

This view of what research *ought to be*, and *ought to do* is illustrated in the work of Simons (2015). Here, Simons (2015, p. xi) highlights the growing perception, at least on a political level, that *evidence* produced via randomized controlled trials is the only type of evidence that should inform and influence policy (see also ► Chaps. 3, “Quantitative Research,” and ► 37, “Randomized Controlled Trials”). Such an inflexible way of understanding the scope and breadth of *evidence* leaves little room for evidence produced via single cases to inform policy and political action. This is perhaps, in part, the result of the domination of the natural sciences model, based on a deductive form of reasoning that affirms anything “outside the system of explained science” to be erroneous (Stake 1995). Clearly, the use of single-case designs that adopt an inductive approach to research is at odds with this natural sciences deductive approach.

This general disregard for the case study is most pervasive in discussions on generalization. The supposed inability for case studies to generalize is, therefore, an important misunderstanding to interrogate. It affirms that there is only *one* way to generalize and that way is *not* from a single case but rather via large samples. Flyvberg (2011) explores this common misunderstanding by way of Galileo’s rejection of Aristotle’s law of gravity (physical theory). The process of rejection did not involve numerous observations but rather two experiments, the first, a *thought* experiment and the second, a *practical* experiment, a case study, leading to a new way of imagining and understanding physics.

Nevertheless, there still remains a general distrust of the case study in particular if it involves a single case. This is remarkable when we consider Karl Popper’s (1959) notion of falsification. It involves conducting a rigorous scientific test in which a proposition is examined, and if only one observation does not fit this proposition, the proposition is either rejected or revised. Such a test renders the case study most suitable for identifying what Popper referred to as the “black swans.” Looking at this scientific test, one can say that a case study is in a unique position to locate these

“black swans” because of its intimate approach to the examination of that under investigation (Flyvberg 2006).

However, we must also recognize the paradox of the case study, as explored by Simons (1986). According to Simons (1986), this paradox is most visible when we consider how a case study can generate both an understanding of the particular though simultaneously generate an understanding of the universal. Case studies can, therefore, partake in both worlds, that of the general and that of the particular (Gerring 2007). This unique quality of the case study, viewed by some as a limitation, is in actuality one of its key advantages.

The many misunderstandings of the case study have generally centered on notions of generalization and subjectivity. While these are important to consider and must be recognized in discussions on the suitability of the case study as a methodology, we must also consider the many benefits of the case study. By doing so, we begin to recognize the artistry of the case study as a methodological contributor to scientific knowledge.

4 The Artistry of the Case Study: Advantages of Case Study Research

The growing shift from a variable-focused approach to causality toward a more case study approach is the result of both a creeping skepticism of standard regression techniques and the desire to preserve the details of individual cases, something commonly lost in large-N type of analyses (Gerring 2006). This has enabled the case study to emerge as quite an attractive alternative to other methods that have typically centered on causality, predictiveness, and traditional forms of generalization.

The case study contributes to our knowledge bases in rather unique and informative ways. It does so via its attention to the local situation and less so on how it represents other cases more generally (Stake 2006). It enables an investigation of complex social phenomena to “retain the holistic and meaningful characteristics of real-life events” without being reductionist (Yin 2009, p. 3). Such an inductive approach considers empirical details that comprise the object of the study.

One of the major strengths of the case study is its distinct ability to uncover the intricacies of complex social phenomena by directing attention to the local situation (Stake 2006). Unlike experiments or surveys that intentionally separate a phenomenon from its context by controlling for particular variables, the case study pays particular attention to contextual conditions. It is a useful method for researchers who seek to examine contemporary events where behavior cannot be manipulated and can also understand the unfolding case over time (Yin 2009).

The epistemological advantage of the case study is that it is a tried and tested approach that offers a rewarding way of contributing to experience by improving our understanding (Stake 1978). Meanwhile, the methodological value of the case study specific to public administration and policy analysis is its ability to draw on many sources and research designs that are largely qualitative (Marinetto 2012). This then

generates a rich narrative allowing researchers a degree of methodological flexibility that encourages theoretical insights.

The value of the case study is also recognized in the theory-building process (Eisenhardt 1989). Eckstein (1975) affirms that the case study is critical to all stages of theory building though most useful when researcher theories are tested. It can add a depth and dimension to theoretical understanding and, by doing so, simplify our understanding of reality (Donmoyer 2000). Largely, the case study can be used to elaborate theory and test theory (Stoecker 1991).

The case study, thus, challenges the supremacy of the natural sciences as the only proper contributor to scientific knowledge. This is eloquently demonstrated by MacDonald and Walker (1975, p. 3) who present the case study as a valuable and unique contributor to human understanding. They poignantly state:

Case study is the way of the artist, who achieves greatness when, through the portrayal of a single instance locked in time and circumstance, he communicates enduring truths about the human condition. For both the scientist and artist, content and intent emerge in form.

Here, MacDonald and Walker (1975) highlight the artistic flair of the case study, emphasize its intense focus on the particular, and, by doing so, position it as a strong alternative to purely quantitative methods for researchers to consider. It offers a different form of knowledge to the researcher, one that is particular, unique and intimate, and free from predictiveness and causation, though bounded by the researchers' subjectivity. The case study, thus, enables the researcher to generalize, not in the tradition sense according to the natural sciences but via the strength available in the description of the content (Stake 1995).

5 A Different Form of Knowledge: The Unshackling

The case study is a creative way to examine and understand the human condition. It allows the researcher to navigate through a process that enables a particular narrative to prevail that is outside the strict confines of empiricism. Here, we see how knowledge has the ability to be transferred without the need to aspire to formal generalization. This section explores what Stake (1978) first proposes as naturalistic generalizations, as a way for the case study to generalize via the reader's experience. It will, however, first interrogate the notion of generalization in its traditional form in order to contextualize the discussion.

5.1 Generalization

Generalization is the transference of what we know and what we learn in one situation to another. It is considered one of the most fundamental goals of scientists. It is almost always linked to terms such as randomness, sampling, statistical significance, reliability, causation, a priori, and so forth (see also ► Chap. 38,

“Measurement Issues in Quantitative Research”). These terms are embedded in traditional forms of research and are comforting to social scientists, largely because many consider no other suitable alternative way to discuss social phenomena (Donmoyer 2000). This unwavering conviction in the power of universal rationality centered on the pursuit of generalizable knowledge is still considered by some as the *orthodox* way to attain *real* knowledge (Schwandt and Gates 2018).

In an attempt to interrogate the view that “nomic” generalizations (centered on prediction) are the only way we can generate scientific progress, Lincoln and Guba (2000) highlight some of the major deficiencies of this type of traditional generalizability while simultaneously providing an alternative, “transferability.” They point to five key problems: “dependence on the assumption of determinism,” “dependence on inductive logic,” “dependence on the assumption of freedom from time and context,” “entrapment in the nomothetic-ideographic dilemma,” and “entrapment in a reductionist fallacy (See Lincoln and Guba (2000, pp. 29–36) for a detailed overview of these deficiencies and of transferability).” These problems highlight some of the deficiencies with the popular nomothetic conceptualization of generalization.

Consequently, this reliance on nomothetic generalization has stymied progress by hindering the way we understand the purpose of generalization as one enveloped by the strict confines of empiricism. This restricted view of generalization, labeled by Donmoyer (2000, p. 46) as both “dysfunctional” and “out of step with contemporary epistemology,” overstates (formal) generalizations as the only way to appropriately contribute to scientific progress.

Statistical generalization, which typically attempts to enumerate frequencies, should not be the goal of social scientists given it is not the only legitimate method of scientific inquiry. Instead, Yin (2014) proposes that the focus should be on analytic generalization. By focusing on analytical generalizations, one can create a proper case, rather than create something to be replicated repeatedly, as is the case with statistical generalization (Patton and Appelbaum 2003; see ► Chap. 38, “Measurement Issues in Quantitative Research”).

We need to examine in more detail this idea of analytical generalization that steers away from generalizations that only refer to notions of prediction. By doing so, we begin to see the value in what Hamilton (1976) describes as a “science of the singular.” While this type of science does not generalize in a propositional sense, its usefulness, because of its focus on the particular by way of narratives and others forms, allows us to learn in different ways and acquire knowledge in ways considered only decades ago as completely unscientific.

This degree of freedom (not in the statistical sense) available via the case study provides social scientists with a flexibility to produce different ways of acquiring knowledge. Eisenhardt (1989) asserts that this freedom is made possible via two ways: one, by the ability for researchers to select a range of different methods and, two, the distinctive “in-depth style” inherent in the case study researcher. Both these ways release the researcher from the shackles of strict procedure, liberate their thinking, and increase the likelihood of generating novel theory. Here, Eisenhardt (1989) allows us to consider the vast possibilities that the case study offers both qualitative and quantitative researchers.

This *unshackling* allows for different types of knowledge, such as tacit, to sit alongside other forms of knowledge and be acknowledged as key contributors to scientific progress. Naturalistic generalizations, as noted by Stake (1978, 1995), can unshackle the researcher and allow them to engage in a different, more visceral form of generalization. The attempt here is not to propose a novel approach but, rather, highlight the need to revisit naturalistic generalizations.

5.2 Naturalistic Generalizations

The case study cannot confidently make “scientific” generalizations, particularly if a researcher intends to use a single-case design as the case is based on specificities such as precise events, locations, or periods of time (Mills et al. 2010). In order to address this limitation, Stake and Trumbull (1982) coin the term “naturalistic generalization,” a proxy process that enables the generalization of findings from a single-case (Stake 1978). This allows a level of generalizability previously not available to the case study, particularly single-case design studies.

5.2.1 Discussion

Naturalistic generalizations are an alternative to the more traditional forms of generalization that center on predictiveness, formality, and keeping propositions intact (Simons et al. 2003). They are quite different to explicated (nomic) generalizations where emphasis is placed on a different type of knowledge. As a result, a humanistic and subjective understanding is more prevalent and even more relevant. They develop within individuals as a product of their individualized and subjective experience with a case.

This understanding comes from tacit knowledge. This type of knowledge is described by Stake (1978, p. 6) as the knowledge of “how things are, why they are, how people feel about them, and how these things are likely to be later or in others places with which this persons is familiar.” This process of generalization may be verbalized, allowing knowledge to transfer from tacit to the propositional, though unable to traverse to the empirical and even logical that typically characterize explicated (nomic) generalizations (Stake 1978). Via such tacit understandings, Stake was able to divert attention to their value in generalizing from a case (Simons 1986).

Stake (1978) claims that explanation is best suited to propositional knowledge, whereas *understanding* is best suited to tacit knowledge. Tacit knowledge is knowledge gained via experiences with objects and events, “experience with propositions about them and rumination” (Stake 1978, p. 5). Polanyi (1958) highlights how individuals harness and contain this tacit knowledge that then allows them to build new understandings of complex social phenomena. While these do not pass logical and empirical tests specific to formal generalizations, they have the ability to guide action.

Naturalistic generalizations are conclusions that provide insights into a case by reflecting on its specific and unique details. They are embedded in the experience of the reader, be it orally or via some other way (Stake 1995). There is a reliance on judgment and interpretation that enables knowledge to be transferred from one

context to another (Simons et al. 2003). This is principally achieved by the reader, who reflects on the particulars and the description contained within a case. The reader then determines how particular details of the case are similar to other situations by drawing on these reflections in order to generalize. The reader then assesses whether these particulars resonate with their personal or vicarious experience and, if so, determines whether the situations are “similar enough to warrant generalizations” (Melrose 2009, p. 600).

Largely, this process enables individuals to form generalizations from their own personal experiences by adding a single case to a repertoire of cases, creating a *different* group from which to generalize. It is, however, important to note that if this process is to effectively take place, the researchers must provide thick description and enough material for the reader to determine the relevance and meaning of this information to their lives.

This process allows findings from one case study to be applied to another similar case study in order to establish useful and relevant understandings (Stake 1978). Such generalizations are then reinforced via repeated encounters (Stake 2005). They are most useful if one seeks to acquire knowledge of the particular. Such a process is described by Stake (2000, p. 22) as both “intuitive and empirical and not idiotic.”

Stake (1978) argues that we must consider the point of view of the user of the generalization. Via the process of naturalistic generalization, which centers on the personal experiences of the user, cases, notably single cases, are able to build naturalistic generalizations (Lincoln and Guba 2000). This “natural experience,” as purported by Stake (1978), is an effective way to add to human understanding and can be achieved via words and images of the natural experience (Lincoln and Guba 2000).

5.2.2 Example

Stake (1995) details practical points that researchers must consider in studies that encourage naturalistic generalizations. These points will assist the reader in providing an opportunity for vicarious experience. They are detailed below (Table 1):

A contemporary example where a case study researcher conducted a narrative and phenomenological case study that encouraged readers to make naturalistic generalizations is *The Wild Food Challenge: A Case Study of a Self-initiated Experiential Education Project [SEEP]*, by Graham McLaren (2015). This study focused on SEEP, a type of self-directed learning that involves a person creating specific goals, commencing the project (this is self-initiated), and following it through to completion. The SEEP was a case of a young adolescent male who attended a school that provided a “deep nature connection mentoring.” Interviews with the student and his mentors revealed the students’ motivations and inspirations and their impact on his own sense of self. The SEEP was presented by way of a narrative account that encouraged the reader to engage in naturalistic generalization by drawing on the particulars of the study to determine ways they can inform their personal experiences. This information may be useful to educators, mentors, and other professionals who design curriculum and educative methods that encourage teenagers to engage in such self-initiated projects on experiential education.

Table 1 A list of things to assist in the validation of naturalistic generalization

1. Include accounts of matters the reader are already familiar with so they can gauge the accuracy, completeness, and bias of reports of other matters
2. Provide adequate raw data prior to interpretation so that readers can consider their own alternative interpretations
3. Describe the methods of case research used in ordinary language including how the triangulation was carried out, especially the confirmation and efforts to disconfirm major assertions
4. Make available, both directly and indirectly, information about the researcher and other sources of input
5. Provide the reader with reactions to the accounts from the data sources and other prospective readers, especially those expected to make use of the study
6. De-emphasize the idea that validity is based on what every observer sees, on simple replication; emphasize whether or not the reported happenings could have or could not have been seen

Source: Stake (1995), *The art of case study research*, p. 87

5.2.3 Critique

Such a different way of generalizing has come under scrutiny over the years. One criticism is that the onus of making naturalistic generalizations is directly placed on the reader instead of the researcher (Hellström 2008; Melrose 2009). It is, therefore, up to the reader to come to their own conclusions using the thick description and context provided by the researcher. This can be viewed as incongruent to scientific induction, a process whereby the researcher, *not* the reader, develops general principles from specific observations.

Other criticisms have focused on the unoriginality of naturalistic generalizations. Hellström's (2008, p. 335) examination of naturalistic generalization concludes that to break this type of generalization from traditional notions of generalizability is unwarranted and even premature. This is largely because interpretivist types of generalizations, such as naturalistic, are "well accommodated" within the broader ambit of generalization. All types of generalizations share the objective of providing a detailed understanding by transferring knowledge from one situation to another (larger population). Therefore, Hellström claims that naturalistic generalization is no different, as it shares this goal with others forms of generalizations.

Another criticism noted by Donmoyer (2000) is that naturalistic generalization emerged as the method of choice for evaluation research and, therefore, its utility and application to other types of research is limited. While Donmoyer (2000) rightly dictates that Stake's conception of naturalistic generalization is underdeveloped, Donmoyer does little to build upon this form of generalization that has merit but requires some development. Donmoyer, however, suggest an alternative conceptualization of generalization specific to single cases, drawing on the conception of experiential knowledge.

While there is much that naturalistic generalizations can offer, and an interpretivist stance toward case studies is beneficial, we should not ignore "power relations or social structures," which Bartlett and Vavrus (2017, p. 33) claim are "underemphasized in Stake's presentation of case studies." The "politics of

representation,” notably “who gets to represent whom and how in a research project,” is not considered by Stake who neglects to consider researcher reflexivity in the research process (Bartlett and Vavrus 2017).

However, as noted by Stake (2000), naturalistic generalization is itself a type of generalization, not in the traditional sense but a type that allows the reader to recognize similarities contained within an object both in and out of context and to be aware of this taking place. Such an engagement with the case will provide for a deeper, more meaningful understanding of the case, one that is tied to the experiences of the reader and one that engages with the reader on a more intimate level. Here, the reader is no longer a bystander, watching from the outside looking in and reading the interpretations of the researcher. Rather, the reader immerses him/herself in the case and develops his/her own interpretations of it. So, when we position naturalistic generalizations alongside nomothetic generalizations, we begin to see that knowledge should not be limited to traditional forms of causation. Instead, knowledge of the particular, knowledge gained via different methodological approaches, is valuable to human understanding of social phenomena.

6 Conclusion and Future Directions

The case study has emerged as an important methodological contributor. It allows for rich theoretical insights that are transferable over time and place. While typically considered a qualitative method, its flexibility and utility have enabled its use in both qualitative and quantitative studies. Such advantages of case study research have made it quite a favorable approach to social science and public health researchers.

While the advantages of the case study are numerous, it has also come under scrutiny, notably in terms generalization. While we must recognize that case studies, notably single cases, are not suitable for traditional (nomothetic) types of generalizations, knowledge can still be transferred even when this knowledge is not generalized in a formal sense (Flyvberg 2011).

Here, we must consider the need to challenge the traditional and rather orthodox thinking entrenched in the way we understand the utility of methods such as the case study. The dominance of natural sciences and the often uncontested approaches to scientific development they espouse have at times hindered the progress of methods beyond the strict confines of empiricism. By contesting such traditional ways of how research *ought to be* conducted, we can allow for and also encourage different types of generalizations as ways to understand that which we seek to examine. One such approach that was canvassed in this chapter was naturalistic generalizations.

We cannot ignore the power of naturalistic generalizations, not as a replacement for nomothetic forms of generalizations but what Stake (1980, p. 2) avers to in his response to criticism by Hamilton (1979), “primarily a creation of [ones’s] own experimental knowing.” This unorthodox approach to generalization allows the researcher to generalize according to the similarities and differences specific to their own experiences, a process Simons et al. (2003, p. 360), have referred to as “individual recipient judgement.”

Naturalistic generalizations are particularly useful to researchers who want to garner the personal and vicarious experiences of their readers. They emphasize a practicality and functionality of research results that draw directly on the experiences of the reader. These accounts are completely subjective and, thus, offer a powerful way to understand the particulars and intricacies of a case directly from the readers' perspective.

A future direction for case study research specific to naturalistic generalizations is that consideration must be given to researcher reflexivity to adequately acknowledge what Bartlett and Vavrus (2017, p. 34) state as the "politics of representation." We cannot ignore that the researcher does play an important role in naturalistic generalizations principally in relation to how information is intended to be absorbed by the reader and how this information is initially represented in the study. This will allow for a more nuanced way to involve naturalistic generalizations in case study research that provides both clarity and openness.

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Evaluation Research in Public Health

20

Angela J. Dawson

Contents

1	Introduction	334
2	Theory-Based Evaluation	335
2.1	The Theory of Change (ToC)	336
2.2	ToC and Classic Change Theories	339
2.3	Realistic Evaluation Theory	340
3	Frameworks to Guide Evaluation Research	340
3.1	Logic Models and Results-Based Frameworks	340
3.2	Other Frameworks to Guide Evaluation	342
4	Purpose and Phases of Evaluation Research	344
5	Evaluation Research Designs	345
6	Evaluation Indicators	345
7	Considerations in the Development of Indicators	347
8	Culturally Appropriate, Gender-Sensitive, Ethically Sound Evaluation	350
9	Conclusion and Future Directions	351
	References	352

Abstract

Evaluation research is concerned with assessing the merit of health projects and programs and produces information for decision-making to improve public health. Evaluation results are critical to continuous quality improvement efforts, building organizational capacity to respond to health needs and ensuring the accountable and efficient use of resources. This chapter will introduce evaluation research to assess the outcomes of health programs and policy. The key characteristics and principles of evaluation will be examined, and the range of

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approaches can be taken in this applied area of research. Examples of process, outcome, and impact evaluation in health contexts will enable readers to:

1. Discuss approaches to evaluation using logic models and theories of change
2. Examine program/project evaluation designs to assess methodological rigor and appropriateness
3. Apply knowledge of global/national/state strategies and public health evidence to guide the development of evaluation indicators
4. Examine the culturally appropriate and ethically sound approaches in evaluation

Keywords

Program evaluation · Theory-based evaluation · Theory of change · Logical frameworks · Results-based management · Evaluation indicators · Gender-sensitive evaluation

1 Introduction

Research and evaluation are often portrayed as a dichotomy, which is not always helpful because evaluation always employs research and, therefore, evaluations are a type of research activity with different timelines and aims. Evaluation research in public health contexts is concerned with assessing the merit of a public health project or a program and produces information for decision-making. These decisions are normally about whether the intervention or set of organized activities that comprise a program should continue to be funded modified or scaled up.

Evaluation research differs from implementation research, clinical efficacy research, and operations research. Table 1 provides an overview of the features of different approach to research including evaluation research.

While often the focus of evaluation research is to improve, it can also be employed to prove that the intervention is in fact responsible for change. Delivering results for and reporting to stakeholders are features of evaluation research that is conducted with the intent to serve the information needs of stakeholders rather than curiosity-driven research. The purpose of evaluation research is, therefore, pragmatic (Patton 2008) and is part of programmatic work often comprising twenty percent or less of the resources.

Evaluation research involves the use of both qualitative and quantitative research methods and methodologies. The study design can be descriptive or experimental, while the focus can be on the effectiveness or efficiency of an intervention and/or understanding the mechanisms that help to support its implementation. According to Habicht et al. (1999, p. 11), evaluations are conducted to determine “plausibility, probability, or adequacy” of interventions. However, all evaluation research in the field of health is applied and part of a cycle of planning, implementing, and assessing interventions that focus on changing people lives including the realization of their rights and improving health outcomes. This may also involve the evaluation of

Table 1 Overview of the features of different types of research

Type of research	Evaluation research	Implementation research	Translational research	Clinical efficacy research	Operations research
Characteristics					
Assess a program implementation	✓				
Assess a program effect	✓				
Identify factors that facilitate implementation effectiveness		✓			
Develop strategies to achieve effective implementation		✓			
How can evidence be applied in practice to affect health outcomes			✓		
Examine how a therapy works on a health outcome				✓	
Construct data-based models for decision-making					✓

behavioral change and institutional change including the organization of components of health systems requiring operational change.

Learning is a key feature of evaluation research described by the European Union (2013, p. 17) as a process of learning through systematic enquiry what public programs and policies have achieved and understand how they perform to better design, implement and deliver future programs and policies.

2 Theory-Based Evaluation

Underpinning all evaluation research is a theory or a conceptual analytical model that provides a way of structuring analysis in an evaluation. A theory is a collection of assumptions and hypotheses that are empirically testable or that are logically connected. In the literature, theory-based evaluation can be found as early as the 1930s (Coryn et al. 2011) and was further developed by key figures such as Chen (1990) and Weiss (1995). Today, theory-based evaluation is commonplace and an integral part of local, national, and international public health practice.

In line with an evidence-based approach to quality public health, we must ensure that our programs are underpinned and guided by principles of public health programming and that evaluation is not an ad hoc enterprise. Theory helps enhance our understanding of complex situations taking into consideration specific contextual factors. Two types of theory can be identified:

- Explanatory theory that helps to identify factors that a health program might try to change
- Change theory that helps us to develop range of intervention strategies to address correct variables in appropriate combination with appropriate emphasis and in evaluation to assess whether all the right components are in place

Theory, therefore, provides a meaningful way for framing or prioritizing evaluation questions. It also provides a guide to the design and execution of the evaluation as well as the interpretation and application of the reported findings. An underpinning theory also allows programs to be generalizable to the larger population and/or transferable to other similar contexts by identifying successful elements and outcomes that can be predicted or anticipated enabling an understanding of what works and why.

A number of organizations including the expert consensus process undertaken by the Agency for Healthcare Research and Quality in the UK (Foy et al. 2011) have called for evaluation research to be integrated into the health program structure from the beginning of the planning phase to build understanding of change. This enables the team to identify which outcomes are key to the program's success and select which ones should be the focus of the evaluation.

Theory in evaluation is often driven by evaluation practice, and many of the theories used have been found to be unsubstantiated by empirical studies (Coryn et al. 2011). Despite this, theory is important to the structure, planning, design, and implementation of the program and execution of the evaluation, and more research is required to deliver exemplars of theory use in evaluation practice.

2.1 The Theory of Change (ToC)

The theory of change (ToC) approach in evaluation is underpinned by concepts of “how and why the program will work” (Weiss 1995, p. 66) and is widespread in public health evaluations (Breuer et al. 2016). ToC as a term in evaluation emerged from social change movements and the work of the Aspen Institute on Community Change. Weiss, who was a key member of this group, described the need to articulate the assumptions upon which each of the steps in a program is based in order to make the change process explicit. ToC is a causal model that explains the complexity of this change by revealing the conceptual framework that explains the causal relationships between program activities and the immediate, short-term and long-term outcomes.

Evaluation theory, therefore, seeks to determine what changes have taken place at each level goal being change at many levels:

- Changes in people's lives such as the achievement of their rights and improvements in health status
- Change in the culture and organization of institutions including their values, the services they provide, legal status, and their performance
- Changes in behavior such as attitudes and practices
- Change in the ways in which products and services are delivered involving improvements in knowledge and skills and cost- and time effectiveness

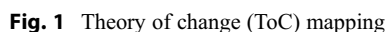
Despite there being a lack of a definition of what ToC is, there is agreement on the important considerations that comprise a ToC (Vogel 2012). These considerations include an explanation of the:

- Context of the initiative, i.e., the sociocultural, political, and environmental conditions, the current state of the problem the initiative is aiming to influence
- Long-term change or impact that the initiative is aiming for
- Process or stages of change expected that will lead to the desired long-term change
- Assumptions about how these changes might occur
- Outputs that are conducive to the desired change in the specific context
- Diagrammatic summary that outlines the change

The process of developing a ToC is usually collaborative and begins with establishing what the far-reaching outcomes or impact will be as the result of a program that are often expressed in terms of the health or social impact (see Fig. 1). This is then mapped to what can be achieved in a long term such as changes in the health outcomes of a defined population and then to the immediate effects of the program upon the beneficiaries themselves. The assumptions or preconditions required to achieve the desired change at each stage are laid bare in a ToC including the contextual factors that may influence these necessary preconditions. The ToC development may also include the design of indicators to assess the change achieved through the program implementation and the evidence required to verify this.

There is considerable literature to guide public health practitioners to develop their own theory of change. This includes guidance from the United Nations (Rogers 2014), philanthropic foundations (Reisman et al. 2004), universities (Taplin et al. 2013; University of Kansas 2017), community organizations (Australian Communities Foundation 2015), and networks (De Silva et al. 2014a).

Theories of change are usually expressed graphically and in a temporal fashion from left to right. Outcomes are noted along the hypothesized causal pathway that is required to achieve the anticipated impact. There are a number of examples in the literature of these diagrams including some in the area of mental health: a theory of change for peer counseling for maternal depression in Goa, India



While Connell and Kubisch (1998) call for credible, achievable, and testable theories of change, Breuer et al. (2016) have developed a useful framework that can be used to report on ToCs in public health evaluations. This consists of four elements outlined below that serve to guide those wishing to develop their own ToC.

- Clear definition of the ToC
- Description of the ToC development process (methods including stakeholder involvement)
- Summary of ToC in diagrammatic form
- Mapping of the ToC to the evaluation questions, indicators used for assessing the program's success, methods of data collection analysis, and data interpretation at various time points including during and after the program implementation.

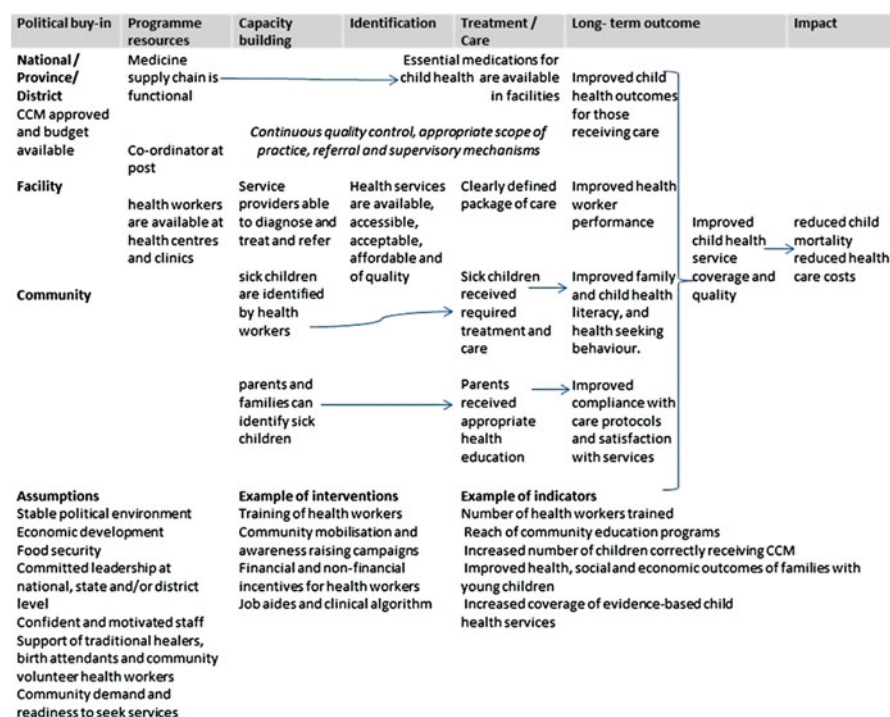


Fig. 2 Theory of change for community case management in Indonesia

2.2 ToC and Classic Change Theories

Theories of change, however, are not rooted in one philosophical tradition; they are pragmatic and can be strengthened by adding theories such as those from sociology or psychology. These theories can be inserted to explain change at various levels and at selected time points either before, during, and after the program implementation.

Some theories focus on understanding the individual factors that influence health behavior, such as knowledge, attitudes, beliefs, and personality traits. For example, Ramsey and colleagues (Ramsay et al. 2010) have used the theory of planned behavior to examine the implementation of a knowledge translation intervention to improve the diagnostic test requesting behavior of general practitioners. A specially designed survey was used to gauge how the intervention affected the attitudes of GPs toward requesting certain tests, their beliefs about others behavior, and perceptions of how easy or difficult it would be to undertake a new regime including the associated contextual factors that would hinder or facilitate this change (Ramsay et al. 2010). Other theories help to clarify processes between individuals and groups such as family, friends, peers, and colleagues to explain social identity, support, and roles. A post-implementation evaluation of a workplace educational program to promote exercise (Amaya and Petosa 2012) used a survey based quasi-experimental design to show the effect of learning by observing others in a social context.

Evaluations that examine changes in communities can use theory to understand how organizational factors such as rules, regulations, and policies affect health or the effect of social norms and networks. The diffusion of innovations theory has been applied in an evaluation of the dissemination of best practice guidelines in substance abuse treatment. The evaluation mapped the effect and rate of the uptake of the guidelines through social networks on health professional knowledge and awareness of the guidelines, how persuaded they were to change their practice, decisions taken toward change, and implementation of the guidelines in services (Hubbard and Hayashi 2003).

Finally, ecological theories attempt to understand the multiple levels and see change in health behaviors, care, services, and policy in terms of a complex system of interrelated factors. The California Healthy Cities evaluation framework sought to measure change at five levels: individual, civic participation, organizational, interorganizational, and community (Kegler et al. 2000). Bauer (1999) employed an ecological model of community organizing to evaluate a capacity and advocacy initiative for residents to impact on public health policy and training of public health professionals.

2.3 Realistic Evaluation Theory

Realistic evaluation is concerned with an examination of the underlying mechanisms and contextual factors that trigger change (Pawson and Tilley 1997). Many evaluation studies have developed a model of change based upon realistic theory to explain what aspects of the intervention bring about change, the extent of this, and the associated contextual circumstances. In Australia, Schierhout et al.'s (2013) evaluation of a continuous quality improvement process in Indigenous health services was able to identify what worked from whom and in what contexts. Similarly Byng et al.'s (2008) evaluation of a multifaceted intervention to improve the care of people with long-term mental illness was able to develop a context-specific, mechanism-based explanations for health-care effectiveness. Realistic evaluation is an iterative process that gradually reveals patterns of outcomes to determine how the program works rather than a focus on what worked.

3 Frameworks to Guide Evaluation Research

3.1 Logic Models and Results-Based Frameworks

Logic models and the more a detailed form known as the logical framework or the logical framework approach (LFA) are tools designed to plan and evaluate programs and describe the goals and resources of an initiative or organization. These tools give less attention to the complex political, sociocultural, economic, and organizational processes that underpin change in health and health care; rather they focus on the implementation of a program. LFAs are useful to plan evaluations and employed as a

metric to understand the aims, plan methods, and indicators for measurement. Theory can be added to strengthen the explanation. Figure 3 lists the logic levels alongside examples of evaluation questions, the indicators employed to measure success, the means through which these indicators are verified, and the underpinning assumptions upon which this change is based.

Spearheaded by USAID, the logic framework (LF) was adopted by many donor agencies and applied across international health settings. In the late 1990s, the UN system adopted the results-based management (RBM) approach in its major agencies. RBM evaluation grew out of the logical framework approach and is a management strategy that focuses on defining results based on appropriate analyses, monitoring progress, identifying and managing risks, capturing lessons learned, and reporting on results achieved and resources involved. The WHO now employs a results framework to monitor the implementation of the organization's program budget, activities, and outputs against its performance according to the achievement of the sustainable development goals (WHO 2017). This approach identifies the monitoring and results-based evaluation phases as well as the responsibility of the WHO Secretariat and member states and partners for accountability and results.

While the diagram at Fig. 4 represents one chain, programs are made of multiple chains that require evaluation. RBM is composed of a series of results chains (see Fig. 5) that, like a logic model, is a simplified picture of an intervention designed in

Logic model	Logic framework evaluation questions	Performance Indicators	Means of Verification	Assumptions
Impact	Goal To what extent have unplanned pregnancies been reduced?	Measures of goal Achievement used for evaluation	Various sources of information; methods used	Assumptions concerning Goal-purpose linkages
Outcome	Purpose/overall objective What increase is there in the use of family planning (FP)?	End-of-project status—to assess purpose achieved Used for project completion and evaluation	Various sources of information; methods used	Assumptions concerning the purpose/goal linkage.
	Component objectives 1. How has knowledge of FP been increased? Is there an increase in the acceptance of FP services? 2. Has the quality of FP counselling and services improved?	Measures of the extent to which component objectives have been achieved for review and evaluation.	Various sources of information; methods used	Assumptions concerning the component objective/purpose linkage.
Output	Output /results 1. Increased availability of educational materials 2. Improved FP supervisory system	Measures of the quantity and quality of outputs and the timing of their delivery. Used for monitoring and review.	Various sources of information; Methods used	Assumptions concerning the output/component objective linkage
Process	Activities 1. Community mobilization activities 2. Mass media campaign 3. Train health workers 4. Quality improvement process	Implementation/work program targets. Used during monitoring.	Project data, other sources of information	Assumptions concerning the activity/output linkage.
Input	Inputs/ Resources Money staff, time, political support			

Fig. 3 Logic framework for the evaluation of a community-based family planning program

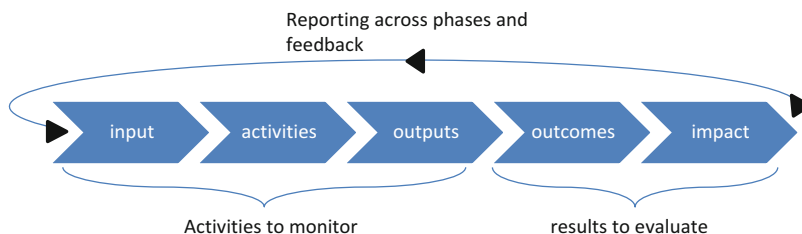


Fig. 4 Results-based management approach to evaluation research

response to a health issue or problem and articulates the logical relationships between the resources invested, the activities, and the stages of changes that result, also known as impact.

The logic model approach and RBM have been criticized for being too focused on a top-down and linear approach that minimizes the characteristics and expertise of people and the interaction of contextual factors on change. However, the strength of this approach is the articulation of the causal connections between conditions that need to change to reach the impact goal. A theory of change can express the assumptions that underpin the results framework.

3.2 Other Frameworks to Guide Evaluation

In the literature, there are many other conceptual models and frameworks that can guide evaluation. The PRECEDE-PROCEED (Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation-Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) model was designed for health promotion planning, and evaluation (Green and Kreuter 2015) has been employed in many public health interventions to evaluate workplace interventions (Post et al. 2015) to individual chronic disease programs (Azar et al. 2017). The Re-Aim (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework (Glasgow et al. 1999) is another useful tool to structure evaluations of individual (Belkora et al. 2015) and community (Jenkinson et al. 2012) and partnership (Sweet et al. 2014) initiatives.

The Centers for Disease Control and Prevention in the United States has developed a Framework for Program Evaluation in Public Health (CDC 1999). This framework summarizes the key elements of evaluation and proposes a six-stage cycle comprised of engaging stakeholders, articulating the program and the evaluation design, gathering credible evidence, justifying the conclusions reached, and sharing lessons learned. This is coupled with standards for effective program evaluation that have been applied in public health disease control programs (Logan et al. 2003).

More recent frameworks include Proctor et al.'s (2011) eight conceptually distinct outcomes for potential evaluation: acceptability, adoption (also referred to as uptake), appropriateness, costs, feasibility, fidelity, penetration (integration of a

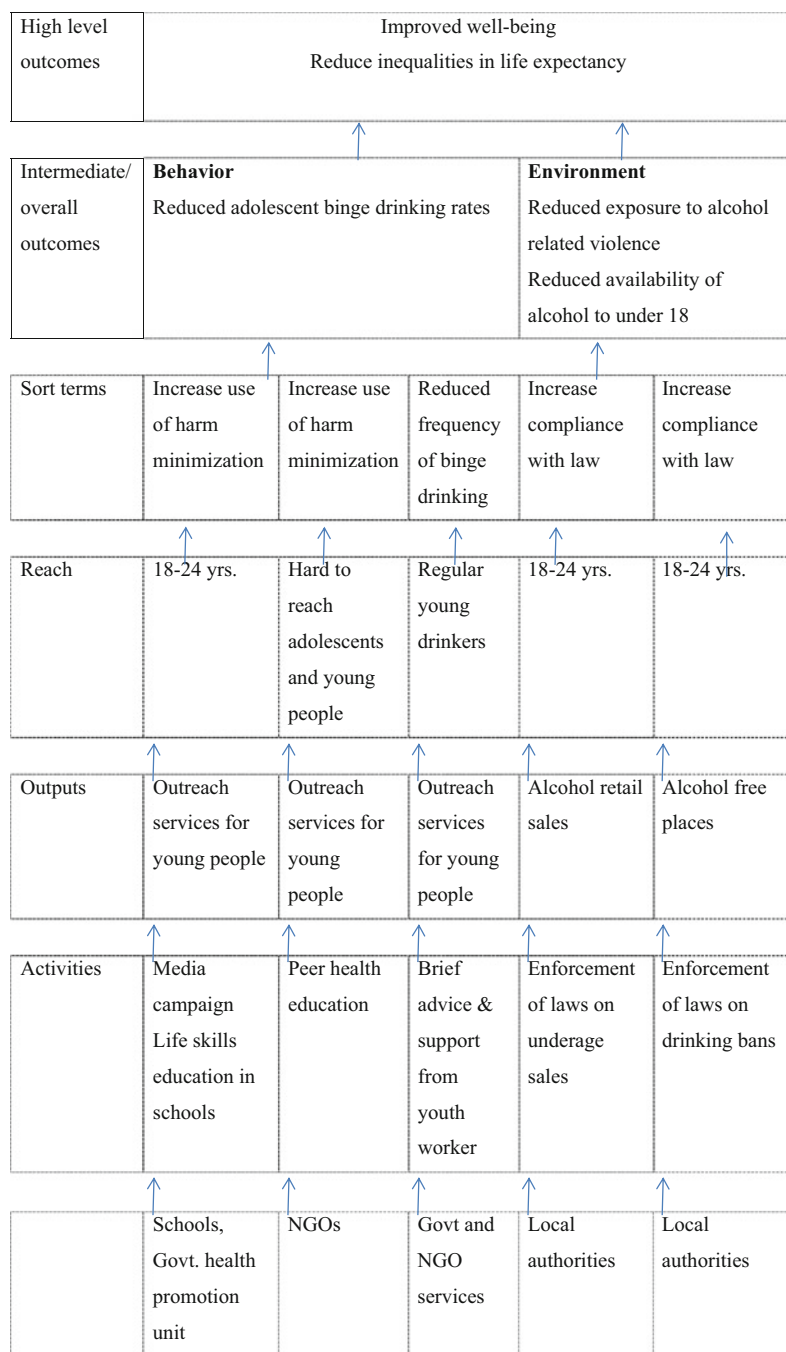


Fig. 5 Results chains for an evaluation of an adolescent alcohol program

practice within a specific setting), and sustainability (also referred to as maintenance or institutionalization). This has been largely applied in implementation research such as the population-based care program for those at risk for delirium, alcohol withdrawal, and suicide harm (Lakatos et al. 2015). Finally, another potentially useful approach to evaluation design is ten steps to making evaluation matter outlined by Sridharan and Nakaima (2011) that add considerations from the realist tradition including sustainability and learning considerations.

4 Purpose and Phases of Evaluation Research

Evaluation may be shaped by the purpose for which it is designed as well as the time frame in which it is executed. As Habicht et al. (1999) suggest, the purpose of an evaluation research can be to establish plausibility, adequacy, or probability. If the aim is plausibility, then the focus will be on designing the evaluation to reveal best how a program achieved its expected objectives and that the change that occurred during the process can potentially be attributed to the program activities. If the aim is to determine adequacy, then this will be an evaluation that seeks to establish if the program goals were achieved. However, an evaluation with the goal of determining probability will most likely employ an experimental design to demonstrate that improved health outcomes or impact is directly attributed to the program activities.

In addition to this, there are several phases or stages of a program implementation where evaluation research can be undertaken as outlined in Fig. 6. This can proceed the design and implementation of a health program or intervention so that baseline data can be collected to not only inform the design of the intervention but also provide a yardstick for measuring change. The next phase of evaluation might involve piloting or testing aspects of the intervention to ensure feasibility, appropriateness, or fit. This process may involve some modification of the intervention and provide additional baseline data. Implementation or process evaluation is known as “real-time” evaluation and involves the regular collection and reporting of information to track whether activities are being implemented and immediate results are achieved as planned (Moore et al. 2015). Theory can be useful to structure this evaluation (Ramsay et al. 2010). Post-implementation reviews take place immediately after rather than during the implementation of an intervention, while outcome evaluation and impact evaluation map short-term and longer-term change, respectively. Outcome and impact evaluation are often termed summative evaluation and

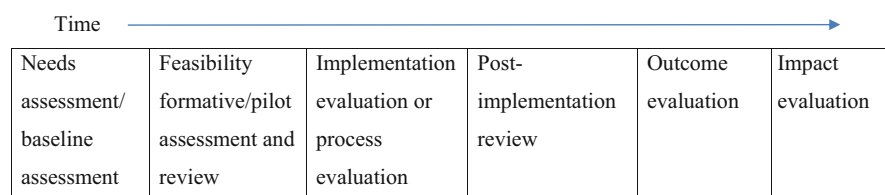


Fig. 6 Phases or stages where evaluation research can be undertaken

aim to answer specific questions about performance of the activities. They are concerned with answering how and why questions linked to plausibility or causality.

There are a number of useful guides to these various types of evaluations in public health contexts provided by departments of health (ACI 2013), international non-government organizations (IFRC 2011), and the United Nations (UNDP 2009; WHO 2013).

Different types of evaluations may be undertaken across these phases that draw on both qualitative and quantitative evidence. Pre-intervention evaluations may comprise assessments of health needs that involve surveys of or interviews with community members or from existing statistical health data, desk reviews of existing reports and policy documentation, or financial audit and risk assessments of the context into which a program or policy may be implemented. Economic evaluations including cost-effectiveness assessment and cost-benefit analysis can be undertaken across all phases alongside quantitative analysis and qualitative evaluations involving observations of behavior, key informant interviews, and participatory processes.

5 Evaluation Research Designs

Selecting the study design for an evaluation depends on the purpose of the evaluation. The purpose will determine the stage or phase where evaluation activities are carried out and the type of evaluation. For example, an evaluation that aims to understand whether the budget was allocated effectively or the performance of health professionals during the implementation of a program may involve systems to monitor the finances or standards over a specific time frame. Other evaluation activities might involve an examination of changes in knowledge or behaviors such as the uptake of contraception. These activities could be part of a process evaluation and employ a quasi-experimental pre-and post-intervention design. Such activities contrast with experimental longitudinal designs where causal links are sought to identify if the program demonstrated an impact on health outcomes of the beneficiaries or the larger population. Impact and outcome evaluation may also involve mixed methods combining, for example, ethnography involving the data collection from in-depth interviews and observation with survey- and/or population-based surveillance data. Table 2 identifies some characteristics and examples of experimental, qualitative, and mixed methods evaluation designs in public health. However, it is possible that an evaluation of a program could be comprised of all or some of these designs and methodologies.

6 Evaluation Indicators

An indicator is a variable that provides accurate and reliable evidence about the achievement of a specific result. Indicators should be observable, well-defined, measurable, and agreed upon. They can be both qualitative and quantitative and are at all levels of the program logic or results chain. Indicators that make up a process evaluation usually involve the regular collection and reporting of data to

Table 2 Study designs and methodologies for evaluation research

Study design	Explanation and example
<i>Experimental and quasi-experimental evaluation designs</i>	
Randomized control trial	The health program's impact is the outcome of interest. Common form involves one group being randomly assigned to receive the intervention, and the other receives no intervention or usual treatment (see also ► Chap. 37, "Randomized Controlled Trials"). Useful when intervention is introduced in small population in highly structured manner, see in the case of the evaluation of a mindfulness program (Hou et al. 2014). Limited by high resource implications and does not necessarily reflect how interventions will work beyond the experiment
Quasi-experimental, comparison group design	May involve a study of a group before and after receiving an intervention. A comparison group could be included. See an example in the evaluation of an urban health initiatives (Weitzman et al. 2002)
Economic evaluation	Statistical measurement of the inputs and outcomes of an evaluation to examine the costs and consequences of an initiative. Sinha et al. (2017) undertook a cost-benefit analysis of a program involving women's groups facilitated by community workers to reduce neonatal mortality in rural India.
<i>Qualitative evaluation</i>	
Ethnography	This methodology involves the study of culture using observation, in-depth interview, and field notes. It involves the researcher spending long periods in the field studying knowledge systems of groups of people (see ► Chaps. 13, "Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology," ► 26, "Ethnographic Method," and ► 27, "Institutional Ethnography"). Ethnography has been applied in the formative evaluation of infant feeding initiatives (Young and Tuthill 2017)
<i>Mixed methods</i>	
Participatory evaluation	An approach that engages stakeholders in design, planning, and undertaking the evaluation with the goal of improving skills and ensuring more responsive health care and services (see also ► Chap. 17, "Community-Based Participatory Action Research"). One example from mental health involves consultation with consumers, community people, and providers to contextualize and validate the findings from case studies (Lea et al. 2015)
Realist evaluation	Theory-driven evaluation to determine the contextual mechanisms that enable the successful achievement of program outcomes. Qualitative and quantitative approaches are employed according to what best answers the questions. Pragmatic design visible in an evaluation of continuous quality improvement in primary health care (Schierhout et al. 2013)
Developmental evaluation	An approach that is responsive to context by allowing constant adaption and enables the gathering of real-time data. Suits complex situations, for example, the evaluation of social change in communities (Patton et al. 2016)

monitor whether results are being realized as planned and to identify problem areas and possible solutions. Such indicators are often found in processes of continuous quality improvement efforts and require an operational definition.

Indicators focused on assessing the achievement of results in outcome, and impact evaluations are analytical efforts to answer specific questions about performance of program activities. There are generally concerned with answering questions concerning why the intended outcomes were or were not realized and how the results were achieved. Such indicators are designed to determine the probability of a program to health and social outcomes over time or the causal contributions of activities to results to confirm a hypothesis.

In Table 3, we can see that the evaluation questions outline in Fig. 3 have been formed into objectives that have been further qualified by indicators across the various evaluation levels. These indicators relate to the provision, utilization, coverage, and impact of health services as well as the legal and social environment. Other indicators can include:

- Improved health outcomes
- Increased use of health facilities
- Extension of quality health services
- Development of human resources for health
- Improved legal environment
- Achieve gender equality

Other indicators could include:

- Improved economic productivity.
- Improved social capital that includes the use of social networks to improve health; this includes the facilitation of cooperation and mutually supportive relations in communities to reduce social isolation, improve well-being and harness the skills and talents of individual, and increase access to employment and education opportunities.
- Improved cultural capital education (knowledge and skills) that provides advantage in achieving a higher social status in society (Table 3).

There is considerable generic guidance on developing quality indicators for evaluation in general; they should be valid, reliable, precise, timely, and comparable. Table 4 defines these attributes using indicators from a family planning evaluation as an example.

7 Considerations in the Development of Indicators

One of the issues of evaluation research is ensuring that everyone involved is applying the same assessment framework to the measurement of outcomes. An operational definition of each indicator is, therefore, required so that those

Table 3 Examples of evaluation objectives and indicators at impact, outcome, and impact levels

Impact evaluation	Impact evaluation indicator
<i>Impact objective</i> Reduce adolescent fertility	Adolescent birth rate (aged 10–14 years; aged 15–19 years) per 1,000 women in that age group reduced by three quarters in country x by 2030
Outcome evaluation	Outcome evaluation indicator
<i>Overall outcome evaluation objective 1</i> Increase adolescent use of modern methods of contraception	Contraceptive prevalence rate in province X increased by x
<i>Overall outcome evaluation objective 2</i> Improved social and policy environment for contraception and sexual and reproductive health and rights	Institution of laws and regulations that guarantee women aged 15–19 years access to sexual and reproductive health care, information, and education
<i>Component 1 outcome evaluation objective</i> Increased uptake of adolescent contraception services	% of new clients and return of clients
<i>Component 2 outcome evaluation objective</i> Improved quality of contraceptive counseling and services for adolescents	% of sites adhering to adolescent friendly standards
<i>Component 3 outcome evaluation objective</i> Increased access to contraception services	% satisfaction
<i>Component 4 outcome evaluation objective</i> Increase availability of contraceptive commodities	% of functional procurement and distribution in the supply chain
<i>Component 5 outcome evaluation objective</i> Increase in female adolescent reproductive health decision-making	Proportion of female adolescents who make their own informed decisions regarding sexual relationships, contraceptive use, and reproductive health care
Output evaluation	
<i>Component 1 output evaluation objective</i> Increased adolescent knowledge and acceptance of modern methods of contraception and service location	% of adolescents with knowledge of available services and commodities Positive attitudes toward contraception and increased expressed demand
<i>Component 2 output evaluation objective</i> Improved health workers contraceptive counseling skills	% of staff trained and assessed as competent
<i>Component 3 output evaluation objective</i> Appropriate clinic opening hours, timeliness of consultation, and appropriate staffing numbers	% of facilities with minimum staffing norms (List of minimum staffing defined)
<i>Component 4 output evaluation objective</i> Health centers stocked with low-cost essential RH commodities	% of facilities without 7-day stock outs of essential drugs (list of essential drugs defined)
<i>Component 5 output evaluation objective</i> Increase in contraception services at health clinics	% of services delivering evidence-based contraceptive services, care, and information to adolescents

Table 4 Attributes of quality indicators

Attribute	Example of indicator
Valid	Participants will recall/describe at least three modern methods of family planning
Reliable	The indicator above could be used and classified as reliable if in pretesting different people (interviewer and participants) demonstrated a consistent understanding of the term “modern.” If not, then validity may be affected since different people may understand different methods as modern
Precise	The indicator must be able to be clearly defined. In this case, a predefined list of modern family planning methods should be able to be produced. The indicator must be precise so that the answers can be clearly assessed
Timely	Change in this indicator could be expected to be within a short time frame. However, if the evaluation sought to measure change in family size in a 2–3-year project, it will not be possible to observe such an indicator within the time frame of the project
Comparable	Knowledge of three modern family planning methods should be comparable across various populations. It should be straightforward to make a comparison between men’s and women’s knowledge of contraception. However, if an intervention-specific indicator was selected, for example, if we wanted to know how many modern methods that adolescents who are peer health educators can list, this is only useful for that group of people but could not be applied to other groups

involved in collecting data can assess the achievement of the indicator in a standard manner. This also requires that the evaluation design is rigorous and aligned with best practice efforts that provide comparable data on changes over time. A protocol is also required to guide data collection, as well as standard tools to collect such data. Piloting or testing indicators in the field with the proposed data gathering tools is useful to ensure that all issues can be addressed before the rollout.

Another area to consider when developing indicators is how they might best connect with existing measures and could be integrated across the health system to provide a useful picture of change. Indicator designs can, therefore, benefit from being aligned with global/national/state strategies and public health evidence. This enables comparability, and although they may need to be field-tested for the unique context of your evaluation, they will already be quite sturdy. For example, countries may already have goals and measures by which they would like to reduce the adolescent fertility rate in line with their Sustainable Development Goals (SDG) targets and measures. This indicator could be inserted at Table 2 to specific the impact evaluation objective and indicator. Other SDG target and goals may also be relevant here such as existing country indicators to achieve gender equality and empower all women and girls.

Some indicators such as the measurement of community participation will require extensive consultation to ensure that what is measured is appropriate and sound. For example, several indicators may be required to evaluate community engagement in a participatory action and learning health initiative. The list below outlines many indicators that could be included in an evaluation.

- No. and % of activities that had a record of community participation
- No. and % activities where community members were involved in identifying the problem or issue
- No. and % activities where community members were involved in determining strategies (deciding what to do) about the problem or issue
- No. and % activities where community members were involved in implementing the strategy (doing the work)
- No. and %. activities where community members were involved in evaluating the results of the work

However, the measures of these indicators will be dependent on the capacity of the community to participate including the skills and knowledge of the people, the strength of the community organizations, and stability of the political and economic context. It is necessary in an evaluation to have buy-in from all sectors, particularly the community to ensure success.

8 Culturally Appropriate, Gender-Sensitive, Ethically Sound Evaluation

Engaging stakeholders including health professionals, decision-makers, and community members before, during, and after evaluation research is essential to ensure that the evaluation questions and indicators are relevant and appropriate and that data is ethically collected. It is critical to include sex, gender, culture/ethnicity, and age categories for data collection as this helps to identify norms, values, attitudes, and behaviors that may affect health and the impact of a program. Gender norms, for example, can be a basis for discrimination and bias. Gender norms around early marriage can work to a girl's disadvantage by preventing their engagement in education and fulfilling employment and predispose them to early childbearing and associated death and disability.

While sex-disaggregated data (data that are collected, analyzed, and reported for men and women and boys and girls separately) is useful, gender-sensitive indicators can be effective in measuring gender or social differences between the sexes. These indicators can measure changes in status, roles, expectations, and norms pertaining to people based on what gender they are or identify themselves as. Gender-sensitive indicators vary in complexity, with some requiring elaborate data collection or analytic methods. Examples of such indicators could be: the proportion of people (disaggregated by sex) who can make decisions about their own health care/health care for their children, or the proportion of people (disaggregated by sex) who experienced physical violence from an intimate partner in the last 12 months. As many of these indicators require the collection of sensitive data, consent and ethical processes are mandatory as is the case of all evaluation research where the results are to be published. However, many evaluations are internal processes that do not require ethical approval. The collection of data against gender-sensitive indicators may also require the employment of field workers of the same gender, culture, and religion to ensure that participants are comfortable in responding.

Effectively engaging stakeholders as equal partners facilitates ownership over the evaluation process and outcomes to ensure that modifications to the program are made during implementation evaluation and lessons transferred in policy and practice.

Thought needs to be given to who should be involved and how this might contribute to the effect of the actual intervention. For example, engaging men in discussions about how the outcomes of a maternal health program might be evaluated or how the results can be applied may increase husband's participation in birth preparedness, a known factor to improve maternal health outcomes. Involving men may also facilitate women's access to facilities in cases where men's approval must be given and finances may be required to travel to a health clinic. Training and involving community midwives in collecting data as part of a maternal health evaluation at village level may provide the most up-to-date information on women who are pregnant in rural situations where data collection is poor.

9 Conclusion and Future Directions

The goal of evaluation research is utilization in policy and practice to improve quality of life. A balance must be, therefore, achieved between quality data and rigorous processes and ensuring that there is ownership and involvement of all stakeholders so that change and health improvement can be actioned.

In the end, the measure of our success will not be predicated on the number of evaluations done, or stored within a database, or even solely upon the quality of the findings... Our success will depend on our ability to use evaluation findings to strengthen our efforts and sharpen our decision-making." (USAID 2011, pp. Rajiv Shah, Administrator, Preface)

Success in evaluation is not always communicated past the reports to funders due to budget and time constraints. However, while sharing lessons learned in peer-reviewed literature is important, so too is the dissemination of evaluation results in the form of practice or policy options briefs for decision-makers. Such dissemination formats help to make evaluation findings accessible and organizations accountable for the resources used. Documenting and sharing evaluation knowledge are, therefore, key to institutionalizing health improvement efforts.

Institutionalizing data-informed decision-making derived from evaluation research is likely to become a key part of future practice with technology playing a central role. Instead of establishing systems to collect data, evaluators are likely to become more involved in data mining and data linkage activities using existing sources that will enable real-time evaluation across multiple sites and countries. The internet may accommodate an increased and participatory approach to evaluation research where citizens and stakeholders can offer comments, contribute data, and undertake analyses. This will facilitate evaluations that capture and respond to the sociocultural diversity in society locally and globally. Evaluation research processes are also likely to become more transparent with activities taking place in

online open access platforms that enable learning to be easily accessed and shared. With these changes may come challenges that could affect the independent nature and quality of evaluation research that standard education and the professionalization of the field can help to keep in check.

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Methods for Evaluating Online Health Information Systems

21

Gary L. Kreps and Jordan Alpert

Contents

1	Introduction	356
2	Formative Research	357
3	Process Evaluation Research	359
4	Summative Evaluation Research	361
5	Conclusion and Future Directions	362
	References	363

Abstract

This chapter will examine the rationale, strategy, and methods for systematically evaluating the effectiveness of online health information systems. Evaluation research will be framed as an essential activity for designing, refining, and sustaining robust health information systems. The best health information system evaluation research programs should include: (1) formative evaluation research activities, such as needs analysis and audience analysis, for designing responsive and appropriate systems; (2) process evaluation research activities to assess how well health information systems work with users, primarily through use of message testing, system usage analysis, and user feedback systems; as well as (3) summative evaluation research activities to assess the influences of the health information systems on important health outcomes, including costs and benefits. We will describe the use of multiple research methods as part of multi-methodological designs for conducting health information system evaluation.

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These methods will include examinations of the applications of content analysis, interviews, focus groups, usability tests, cost-benefit analysis, user feedback systems, unobtrusive measures, the critical incidents method, and field experiments for evaluating health information systems.

Keywords

Evaluation research · Health information systems · Formative evaluation · Process evaluation · Summative evaluation · Multimethodological research · Audience analysis · Needs analysis · Cost-benefit analysis

1 Introduction

Powerful new online health information technologies (HITs) have been touted as holding tremendous promise for enhancing the delivery of health care and promoting public health (Kreps 2011a, 2015). The tremendous growth and widespread adoption of online health information systems, such as health care system portals, health information websites, and online support groups, has the potential to transform the modern health care system by supplementing and extending traditional channels for health communication (Kreps 2015). The use of new health information technologies can enable broad dissemination of relevant health information that can be personalized to the unique information needs of individuals (Neuhauser and Kreps 2008). These ehealth communication channels can provide health care consumers and providers with the relevant health information they need exactly when and where they need the information (Krist et al. 2016).

Unfortunately, many of the enthusiastic predictions about the amazing contributions of digital health programs for promoting public health have not reached fruition and the great potential of health information systems has resulted in limited returns (Kreps 2014a, b). Too often, health information technologies fail to communicate effectively with users due to problems with the design of messages and the usability of the technologies (Neuhauser and Kreps 2003, 2008, 2010; Kreps 2014b). There is a long way to go for digital health information systems to reach their incredible potential. To enhance the quality of online health information systems, rigorous evaluation research needs to guide the design and refinement of these systems (Kreps 2002, 2014a, c; Alpert et al. 2016b). It is critically important to conduct regular, rigorous, ongoing, and strategic evaluation of health communication programs to guide development, refinement, and strategic planning (Rootman et al. 2001; Green and Glasgow 2006).

Failure to engage in careful and concerted evaluation research is likely to doom the success of online health communication systems (Kreps 2002, 2014a). Evaluation research answers important questions about the specific influences online health communication programs have on different audiences, identifying which audiences are paying attention to the programs and what they are learning from the programs (Kreps and Neuhauser 2013; Kreps 2014a). Evaluation data can identify when online health communication programs are having any unintended influences,

including boomerang and iatrogenic (negative) effects (Rinegold 2002; Cho and Salmon 2007). Poorly designed health communication programs have had negative influences on key audiences, such as with the infamous National Youth Anti-drug Media Campaign, which instead of combating youth drug abuse, actually increased interest in using illegal drugs by at-risk youth (Hornik et al. 2008). Well-conducted evaluation research can help explain why some programs work and what parts of these programs work the best (Kreps 2014a).

2 Formative Research

Formative evaluation research is conducted prior to the introduction of health information systems to guide the design of these programs (Kreps 2002, 2014a). Formative evaluation helps health information system designers answer key questions about the goals and purposes of the programs they are developing. Revealing formative evaluation data can clarify what system designers want to accomplish with specific communication programs, which audiences they want to reach and influence, and what they want audience members to do in response to the health communication programs. Formative data can provide essential information to system designers about the audiences they want to reach, such as what health issues audience members are likely to be interested in, what audience members currently know about key health issues, and which messages are likely to make sense to and resonate with different audiences. Formative evaluation data can be used to establish measurable goals and outcomes for online health information programs. Formative data can be used to establish baselines for establishing current levels of knowledge and health activities to track over time. Formative evaluation research can guide adoption of relevant theories and intervention strategies to guide development and implementation of health information systems. Furthermore, good formative evaluation research can also help ensure that communication programs are sensitive to unique audience needs, cultural orientations, literacy levels, and expectations (Neuhauser and Paul 2011; Kreps 2014a).

There are two primary and interrelated forms of formative evaluation research that are critically important to the design of health information systems: needs analysis and audience analysis (Kreps 2014a, c). Needs analysis is conducted to help systems designers develop a full understanding of the scope of health issues, health behaviors, and current knowledge about the health issues confronting different audiences. Needs analysis data help system designers focus on the most relevant health issues with their programs and provide audiences with the most useful and up-to-date health information. It helps system designers determine the gaps between what is currently happening related to specific health issues within different communities and what needs to happen to promote health.

Needs analysis data can often be collected through use of multiple research methods, such as secondary analysis of existing data, such as reviewing relevant epidemiological studies about disease incidence and outcomes, surveys about health issues confronting different communities, public and private health utilization

records, and research reports about best practices for addressing specific health issues (Kreps 2011b, 2014a; Alpert et al. 2016a). Sometimes, when there is insufficient research that has already been conducted about specific health issues and trends, new data should be collected to fully evaluate the health issues within specific communities. New needs analysis data can be collected with surveys, interviews, and observations. Both quantitative and qualitative needs data can help health information systems designers develop a full understanding about relevant health issues. Situation analysis is a form of needs analysis that examines the history and extent of specific health issues within communities, focusing on how widespread the health issue is, who the health issue affects, how the issue has been treated, and what recommendations have been made for ideal ways to address the health issue (Rootman et al. 2001). Channel analysis is a form of needs analysis that focuses on examining the current health information systems in effect within communities and how effective these channels have been in disseminating relevant health information (Rootman et al. 2001). SWOT analysis (strengths, weaknesses, opportunities, and threats) is a needs analysis framework that focuses on identifying and analyzing the internal and external factors that can have an impact on addressing community health issues (van Wijngaarden et al. 2010). Needs analysis is essential for helping systems developers understand the nature of the health issues that their health information systems are designed to address. It also indicates the kinds of information that is needed to address different health issues (Kreps 2014a).

Audience analysis is another form of needs analysis that focuses on providing information about the different key populations that health information systems designers want to reach and influence (Kreps 2014a). Audience analysis should provide system designers with information about which groups of people are at greatest risk for different health threats, what they currently know about key health threats, and what they need to know. It tells system designers what beliefs, attitudes, and values key audiences hold relevant to the health issues to be addressed, how the audiences have responded to health issues in the past, what channels of communication they use for accessing health information, and how effective these channels have been at providing them with accurate, relevant, and up-to-date health information. Audience analysis also provides data about relevant communication characteristics of different key audiences, such as the primary languages they use (are they native English speakers or do they use another language), their health literacy levels, their levels of trust in different information sources, and their receptivity to information about different health issues. Audience analysis data are essential for guiding the design of health information systems.

Audience analysis data help system designers segment the most relevant and homogenous audiences for different health information systems, so the information systems can be designed to be meaningful and influential for these populations. This means that health information systems are often best designed for specific audiences and one size does not necessarily fit every audience (Kreps 2012). Audience analysis data are typically collected with interviews, focus groups, and surveys to gather self-report information from different populations. Sometimes key documents are analyzed, such as websites, online posts, letters, and newspapers through content

analysis to examine key audience beliefs and attitudes. Secondary analysis of relevant surveys, such as the Health Information National Trends Survey (HINTS), can also provide relevant audience analysis data (Hesse et al. 2005; Finney Rutten et al. 2011). In addition, observational data can provide insightful audience analysis data for guiding design of health information systems. Formative evaluation research provides rationale and direction for the design of health information systems that address important health issues and provide relevant and up-to-date health information and reflects the unique cultures, communication orientations, and health information needs of intended audiences (Kreps 2014a).

As social media has become a vital channel for online health communication campaigns, it can also be leveraged as a powerful tool during formative evaluation research. In general, web-based tools like social media have advantages over in-person methods because physical barriers can be overcome, searchable content makes it convenient to find specific information, and the medium encourages interactivity (Chu and Chan 1998). Social media reaches large and specific audiences and among public health departments, 60% employ at least one social media application, with nearly 90% using Twitter and 56% utilizing Facebook (Thackeray et al. 2012). Facebook is the most popular social network for individuals, including 62% of adults 65 and older who have joined (Greenwood et al. 2016). Other applications like Twitter, Pinterest, and Instagram are gaining popularity and tend to be used more by online adults ages 18–29 (Greenwood et al. 2016).

Eliciting feedback or input from users can be collected from reviewing websites, blogs, or social networking groups. For instance, collecting needs or audience analysis from a population segment that has experience with a particular health topic can be accomplished by posting a question on a Facebook wall to trigger a discussion (Neiger et al. 2012). This method is particularly effective to gather insights from hard-to-reach populations or when stigmatized issue is concerned. For instance, a discussion was created on a popular social networking website to understand teenagers' HIV prevention strategies (Levine et al. 2011). This technique enabled the researchers to capture the exact language used by teenagers and was a convenient and low cost means of collecting valuable insights.

3 Process Evaluation Research

To ensure that online health information systems achieve their health communication goals, it is important to test key program components. This is known as process evaluation research (Moore et al. 2014). Health information programs are carefully assessed to determine their suitability for addressing specific health issues. User responses are tracked to determine whether health information programs are working well with different audiences. Tests are often conducted to determine the adequacy of message strategies used and the communication channels deployed to disseminate health messages. Field tests are conducted to determine how well the intervention programs have been implemented in key settings. User responses to programs are tracked over time, especially after refinements are made to the programs. Programs

are tested to determine how acceptable and usable they are for key audience representatives. These tests often generate user recommendations for refining program features that can be implemented to improve intervention programs. Process evaluation can identify strategies to improve the quality and delivery of online health systems.

Process evaluation data can be collected with user-response systems, such as questionnaires, interviews, or focus groups, which ask representative program participants about their experiences using the health information system, as well as their evaluations of the strengths and weaknesses of program components. These tools are sometimes referred to as user satisfaction surveys. The Critical Incident Method is a sophisticated qualitative user-response system for process evaluation that asks representative users about the best and worst elements in health information systems, leading to in-depth recommendations for emphasizing the strongest parts of health information systems and refining the weaker elements of the information systems (Alpert et al. 2016c).

Message testing experiments are also often used to assess user responses to messages, such as how much they liked the messages, how informative, how believable, and how influential the messages were. Respondents are typically asked for suggestions for revising the messages to make them clearer, more interesting, and more influential. A/B testing is a message testing strategy that compares two versions of a webpage or application against each other to determine which one performs better. Sometimes eye-tracking tests are conducted to determine which messages respondents focus on and which messages they find most arousing. There are also standardized text analysis programs that are used to assess readability levels of system content, such as the CDC's Clear Communication Index (Alpert et al. 2016a).

Usability tests are often conducted to determine how well different representative users can navigate online health information systems (Nielsen 1999; Kreps 2014a). In these usability tests, representative system users are asked to demonstrate how they use the system, showing how they can find specific information on the system. Researchers often will ask respondents to comment on how easy or difficult it is for them to find information and navigate the system during the usability tests, inviting respondents to suggest better ways to design the information system to make it easier to use. The data provided from the usability tests can be very revealing about hidden system flaws and about strategies for refining system design. For instance, an exercise simulation called BringItOn aimed to increase physical activity for health, recovery, or rehabilitation purposes (Albu et al. 2015). Usability testing included heuristic expert analysis and think-aloud verbal protocol. Heuristic analysis is when an expert, in this case, a software engineer, evaluates an application and compares it to the industry's best practices (Nielsen 1994). Think aloud verbal protocol is when an individual describes their decision-making criteria during a problem-solving task (Fonteyn et al. 1993). Based on these methods, BringItOn revised the software to better fit the needs and wants of participants.

In addition to usability tests, system usage data are tracked to identify who uses the information system, how often they use the system, and how much time they spend interacting with the system (Kreps 2002). Tracking data can often be collected

unobtrusively through analysis of system use and billing records. Also, website usage metrics and surveys can be used to measure levels of reach and engagement (Nguyen et al. 2013). This type of process evaluation was utilized in The FaceSpace Project and metrics provided objective data about audience characteristics and timing of their engagement. Survey data explained users' online behavior and sexual behavior, while team meeting notes kept records of the challenges associated with conducting a sexual health promotion using social media (Nguyen et al. 2013). While usage data are interesting, it is often necessary to question users directly to find out why they use the system, how well the system works for them, and whether the information they accessed from the system influenced their health decisions, behaviors, and outcomes (Webb et al. 1972; Kreps 2014a). Process evaluation research is critically important for tracking user responses to health information systems over time and for providing evidence for refining system components to meet the needs of system users (Kreps 2002).

4 Summative Evaluation Research

Summative evaluation research is used to measure overall influences and outcomes from online health information systems. Summative research is conducted after the information system has been in use for a substantial period of time to document the positive and negative influences the information system has had on addressing health issues. Many of the evaluation research methods that were used in conducting both formative and process evaluation research on the information system are conducted again to compare system performance over time. By comparing baseline (pre-test) data on audience member's beliefs, attitudes, knowledge, behaviors, and health status with outcomes (post-test) data on these same factors, a quasi- experimental field test can be conducted to assess changes that have occurred during use of the health information system. These changes can be compared to measures of comparison groups that did not have access to the health information system to illustrate whether changes that occurred with the test group were related to system use. The summative evaluation data that are collected can provide important measures of the overall utility of online health communication programs for addressing important health issues and promoting public health (Nutbeam 1998; Kreps 2002, 2014a).

Summative data should examine overall patterns of program use, user satisfaction with programs, message exposure and retention from the programs, changes in key outcome variables (such as learning, relevant health behaviors, health services utilization, and health status) related to the intervention, as well as economic analyses of program costs and benefits (cost-benefit analysis). Summative research also identifies strategies for sustaining the best intervention program. Strong summative evaluation data can be very influential in determining the overall value of the health information systems, directions for improving systems, and securing support for program sustainability and institutionalization (Kreps 2014a).

A way of bolstering summative evaluation of online health communication campaigns is to utilize social media and track web analytics, or key performance

indicators (KPI). KPIs are metrics that assess pre-established goals of a social media campaign (Sterne 2010). Metrics such as the number of clicks, shares, mentions, and followers can be used to gauge a variety of KPI's, like interaction and awareness. Other KPIs include exposure, or the number of times content on social media is viewed; reach, the number of people who have contact with the social media application; and engagement, which is participation in creating, sharing, and using content (Neiger et al. 2012). Based on a campaign's goals, KPIs should be identified and defined during the formative and process evaluation research stages. To monitor KPIs, typically a social media performance dashboard is used, which is an insight tool that monitors media performance and provides guidance for program enhancement and optimization (Murdough 2009).

Social media provides a wealth of information that could be evaluated both quantitatively and qualitatively. Summative evaluation dashboards can be used to evaluate reach, discussions, and general outcomes. Reach focuses on several factors, including the volume of mentions, where mentions are occurring (e.g., Twitter, social networks, blogs, discussion forums), and the social influence of individuals discussing the issue (Murdough 2009). Discussions identify the main topics or themes, the tone of discussions (e.g., positive or negative) and whether sentiment has changed (Murdough 2009). In an example of a qualitative approach utilized social media to inform the public about food safety, comments from Facebook walls were monitored, which provided a rich source of how individuals interacted with the information and took action or changed behavior (James et al. 2013). Quantitatively, different forms of engagement were measured in a Facebook study focusing on chronic disease (James et al. 2013). Metrics included the number of "likes" and "shares" to determine low, moderate, or high levels of engagement (Rus and Cameron 2016).

5 Conclusion and Future Directions

Evaluation research should be an indispensable part of the development and refinement of every online health information system (Rootman et al. 2001; Kreps 2014a). It is critically important to utilize user experience in designing and refining health information systems; this is known as participatory or user-centered design, and it not only provides important insights into audience experiences with information systems, it also encourages user involvement with the information systems (Neuhauser 2001; Neuhauser et al. 2007; Neuhauser and Kreps 2011, 2014). The best health information systems are designed to reflect the experiences and insights of system users (Neuhauser et al. 1998).

Evaluation researchers should carefully identify available sources of audience analysis data. What do we already know about key audiences? Are there natural sources of information about key events that can inform evaluation efforts, such as medical billing records, public records, or message transcripts? Health information system designers should build in user-response mechanisms into every online health communication intervention program to provide user feedback about program use.

Researchers should carefully identify existing sources of data about key audience attributes and behaviors to use as benchmarks for later comparisons after use of health communication programs, or establish new data collection measures to establish key baselines and track use over time. Usability tests should be conducted regularly to determine the effectiveness of communication programs for different groups of users. Researchers should work closely with key representatives from targeted audiences to conduct user-centered design and community participative evaluation research (Neuhauser et al. 2007). Data from evaluation research should be applied to refining and improving all digital health communication programs.

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Translational Research: Bridging the Chasm Between New Knowledge and Useful Knowledge 22

Lynn Kemp

Contents

1	Introduction	368
2	What Is Translational Research	369
3	Translation in Health Social Science Research	372
4	Translation from Basic Theory and Evidence to Human Studies	373
4.1	T0: Theoretical Research	374
4.2	T1: Translation to Humans	375
4.3	T2: Translation to Clients	375
5	Translation of New Practices/Programs into the Clinic/Community, Health Decision-Making, and Implementation Research	377
5.1	T3: Translation to Policy and Practice	378
5.2	T4: Translation to Community	380
6	Critical Elements of Translational Research	383
6.1	Attention to External Validity	383
6.2	Understanding Both Whether Program Effective and Why	384
6.3	Collaboration and Community Engagement	385
7	Conclusion and Future Directions	386
	References	387

Abstract

The failure to translate health research findings into practice costs lives. Less than 20% of research on the efficacy of new interventions or practices finds its way into ongoing clinical practice, and it takes between 15 and 20 years for this translation to occur. Translational research involves a series and combination of methods to achieve the nonlinear process of progressing basic scientific discovery to a

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367

healthcare intervention, to the assessment of efficacy of that intervention for health outcomes in trial groups, to the determination of effectiveness of the intervention in the broader population, and finally to the sustainable adoption of the effective practice at population scale. More simply put, translational research is the movement of basic science into human research and human research into healthcare practices: the former sometimes referred to as translational research and the latter as implementation research. This chapter will provide some clarity to the complex labeling and conceptualizing of translational and implementation research and their methodological frameworks including the characteristics and key procedures of research methods that facilitate quality and timely translation of interventions and programs, including hybrid and reflexive research designs, diffusion and dissemination research, and decision-making and policy research.

Keywords

Translational research · Hybrid trial designs · Pragmatic trials · Decision-making tools · Fidelity research · External validity · Collaboration

1 Introduction

To him who devotes his life to science, nothing can give more happiness than increasing the number of discoveries, but his cup of joy is full when the results of his studies immediately find practical applications. (Louis Pasteur cited in Brownson et al. 2012, p. 3)

Increasingly, research funders, the public, and policy-makers are demanding that the significant investments made to conduct health innovation research result in measurable patient and/or population improvement and show a return on research investment (Brownson et al. 2012; Institute of Medicine 2013). Internationally, assessments about quality in research are adding engagement and impact measures to traditional measures such as publication in academic journals. For example, the Australian government, through its National Innovation and Science Agenda, has piloted assessment of engagement and impact of university research to its Excellence in Research for Australia (ERA) assessment (Australian Government 2017). Some writers have suggested that researchers engage in what they term “Designing for Dissemination and Implementation” (D4D&I), which “refers to a set of processes that are considered and activities that are undertaken throughout the planning, development, and evaluation of an intervention to increase its dissemination and implementation potential” (Brownson et al. 2012, p. 34). These initiatives are designed to address concerns that too little research results in benefit to patient care, and on average it takes 17 years for this small proportion of research to be ultimately translated and implemented in healthcare settings (Green et al. 2009; Morris et al. 2011).

Further, once translated, there is considerable evidence from many fields that the quality of implementation is poor and that programs are subject to reduced fidelity and poorer outcomes (Bopp et al. 2013; Moore et al. 2013). Programs and

interventions loose effectiveness due to “drift,” defined by Aarons et al. (2012, p. 2 of 9) as “a misapplication or mistaken application of the model, often involving either technical error, abandonment of core and requisite components, or introduction of counterproductive elements.” They are also subject to dilution. For example, evaluation of the US implementation of 35 various early childhood home-visiting programs by Daro et al. (2014) showed that retention at 12 months ranged from 3.9% to 73.0%, the proportion of families receiving the full dosage ranged from 5.3% to 26.4%, and the proportion receiving 80% of dosage ranged from 41.2% to 51.6%. A study of five program models implemented nationally in the USA found that only 53% of families were retained until the child was aged 12 months and less than 20% of enrolled families received the recommended number of visits (Latimore et al. 2017). Earlier evaluations found that no matter what home-visiting model was implemented, families typically receive about half of the models’ intended dose (Gomby 1999).

There is concern that to date translational research has both lacked investment and been poorly conducted. As the field has emerged, there has been a plethora of models and tools to support translational research; however, this has contributed to confusion rather than adequate investment and quality science. In addition, there has been a lack of attention to translation research in the health social sciences, both in terms of the translation of social interventions (as opposed to clinical interventions) and despite the social sciences being critical to the success of translational research.

This chapter will clarify the language of translational research, provide a social intervention translational research parallel for the oft-presented and more widely understood clinical translation methods, and highlight the role of health social science in translational research.

2 What Is Translational Research

Translational research means different things to different people but it seems important to almost everyone. (Woolf 2008, p. 211)

Translational research developed alongside the evidence-based medicine movement, as a framework to more systematically detail the research processes of moving discoveries and clinical innovations from “bench-to-beside.” The website of the US National Institutes of Health (2007) has offered the following definition:

Translational research includes two areas of translation. One is the process of applying discoveries generated during research in the laboratory, and in preclinical studies, to the development of trials and studies in humans. The second area of translation concerns research aimed at enhancing the adoption of best practices in the community. Cost-effectiveness of prevention and treatment strategies is also an important part of translational science.

The framework for clinical translation was thus initially conceptualized as having two types (Institute of Medicine 2013):

- Type 1 translation of basic science (e.g., cell and chemical studies) to humans: classically the creation of new drugs or technologies and their initial human studies
- Type 2 practice-based research: conducting efficacy (trials in very controlled settings) and effectiveness (trials in real-world settings) studies

Type 2 translational research was “divided” into T2 and T3, to be inclusive of the additional processes required for broader practice-based research to support dissemination and adoption of innovative clinical treatments, detailing:

- T2 translation to patients: covering systematic review and guideline development
- T3 translation to practice: with dissemination and implementation research

Facing criticism that these “types” were still not descriptive of the full process from basic research to patient trials, and particularly failure of the framework to include broader population adoption, a more recent framework describes five (5) types of clinical translational research (T0–T4), within two domains (Institute of Medicine 2013):

- Translational from basic science to human studies:
 - T0: Basic science research
 - T1: Translation to humans
 - T2: Translation to patients
- Translation of new data into the clinic and health decision-making:
 - T3: Translation to practice
 - T4: Translation to community

Figure 1 shows these frameworks and how they equate, together with details of the forms of research in each type. Not depicted in the figure is the reflexive dynamic that should exist across all the types of translational research. Rather than a unidirectional movement from T0 to T4, the learning from subsequent translation should inform earlier types. It is this lack of reflexivity that can contribute to the conduct of trials that test treatments or interventions that are either not relevant to or unable to be implemented in the real world. This can be the result of the failure of clinical research to consider the importance of delivery processes and contexts.

Clinical research has a prime focus on internal validity, that is, being able to “prove” that the intervention *alone* is responsible for the outcomes produced: context and processes are “noise” that needs to be controlled (Blamey and Mackenzie 2007). However, in a reflexive translational research framework, they are considered an interactive part of both the intervention and the research processes that are necessary to conduct “translatable” research. Box 1 provides an example of nonreflexive and reflexive clinical research, highlighting the enhanced translatability of the reflexive research.

Figure 1 also depicts the research funding investment in the different types of research. Despite increasing recognition of the importance of translational research,

Fig. 1 Phases of translational research

	BENCH	Type 1 Translation to humans	BEDSIDE	Type 2 Practice-based research	PRACTICE
CLINICAL INTERVENTION RESEARCH	Basic research	Case Series Phase 1 and 2 clinical trials	Human clinical research Controlled observational studies Phase 3 clinical trials	Phase 3 and 4 clinical trials Observational studies Survey research	Clinical practice Delivery of recommended care to the right patient at the right time
			T2 Translation to Patients	T3 Translation to Practice	
			Guideline development Meta-analyses Systematic reviews	Dissemination research Implementation research	
	Translation from basic science to human studies			Translation of new data into the clinic and health decision-making	
	T0	T1	T2	T3	T4
	Basic science research	Translation to humans	Translation to patients	Translation to practice	Translation to community
	Pre-clinical and animal studies	Proof of concept Phase 1 clinical trials	Phase 2 clinical trials Phase 3 clinical trials	Phase 4 clinical trials and clinical outcomes research	Population-level outcomes research
	Defining mechanism, targets, and lead molecules	New methods of diagnosis, treatment, and prevention	Controlled studies leading to effective care	Delivery of recommended and timely care to the right patient	True benefit to society
	Current research investment			Research investment needed	
	Translation from basic theory and evidence to human studies			Translation of new practices/programs into the clinic/community, health decision- making and implementation research	
SOCIAL INTERVENTION RESEARCH	T0	T1	T2	T3	T4
	Theoretical research	Translation to humans	Translation to clients	Translation to policy and practice	Translation to community
	Evidence and theoretical reviews	Proof of concept and pilot studies	Hybrid research models and pragmatic trials	Adoption studies Comparative effectiveness studies	Action research Population-level implementation and outcomes research
	Defining mechanism, outcomes, and theory of change	New methods of diagnosis, treatment, and prevention	Controlled studies leading to effective care	Delivery of recommended and timely care to the right clients	Sustainable, quality adoption and outcomes

Box 1 Nonreflexive and reflexive clinical research

Nonreflexive	Reflexive (Designing for Dissemination and Implementation (D4D&I))
Researchers at the New Drug Institute have developed a new drug treatment (T0, T1) and are conducting their phase 2 clinical efficacy trial (T2). With a strong focus on internal validity, in order to prove the efficacy of their new drug, they are running a randomized controlled trial to test the <i>drug</i> with their target population in the outpatient rooms at the local specialist hospital	Researchers at the New Drug Institute have developed a new drug treatment (T0, T1) and are conducting their phase 2/3 clinical efficacy and effectiveness trial (T2). With a focus on both internal and external validity, the researchers have asked health providers and patients what they need and what would work for them (T4). In conducting the trial, they have tested the <i>drug and the delivery mechanisms</i> and they importantly included a range of patients who are representative of those who would use the drug (T3)
A few years later, the trial results show that the <i>drug</i> is efficacious and results are published. Some further years later, the drug has been in use across the country; however, questions are being raised about its effectiveness as health providers and patients are not seeing the results that the trial suggested should be expected. Research is conducted that shows that providers and patients are reluctant to try the new drug and that there are problems with the drug ordering and delivery processes, so patients are not using the drug with the needed consistency	A few years later, the trial results show that the <i>drug and its delivery mechanisms</i> are effective and it is widely adopted and in effective use in the community

it remains of considerable concern that the majority of research investment is in T0 through T2 research, despite, as noted by Woolf (2008, p. 212):

[P]atients might benefit even more – and more patients might benefit – if the health care system performed better in delivering existing treatments than in producing new ones.

3 Translation in Health Social Science Research

To date, translational research has been largely considered the domain of clinical research. The development and implementation of social interventions in health, for example, health promotion and behavioral interventions, has not been subject to the same scientific rigor as clinical research, with assumptions that social interventions are done with “good intentions” and so science is redundant. The aphorism “the road to hell is paved with good intentions” is pertinent here, as social interventions, which are often implemented on a community or population scale, can have significant and generational benefits or harms. For example, the social intervention of placement of children of unwed mothers into care, based on evidence [assumptions] and good intentions that life chances for children are better in families with married parents, has resulted in generational trauma for which many governments have subsequently apologized.

The lack of rigorous science in social health intervention research has been mirrored by a lack of funding for such research. There is increasing recognition of the need for science in social health that is equivalent to that used in clinical research. Frameworks for rigor and methods for specific phases in the development, trialing, and implementation of social health interventions are now beginning to be developed, and greater investment is needed. Figure 1 shows the social health intervention parallels for the types of translations research T0 through T4, within the two domains of:

- Translational from basic theory and evidence to human studies:
 - T0: Theoretical research
 - T1: Translation to humans
 - T2: Translation to clients
- Translation of new practices/programs into the clinic/community, health decision-making, and implementation research:
 - T3: Translation to practice
 - T4: Translation to community

In addition to this redefinition of the types of translation research to encompass social, rather than clinical, interventions, health social science has a considerable contribution to make in T3 and T4 translational research. The use of social science is fundamental to translation to practice and community of both clinical and social interventions.

Best practice research studies, strategies, and frameworks for translational research in social interventions, and the use of social science methods to enhance T3 and T4 translation, regardless of the intervention type, will be discussed in the remainder of this chapter. The example of the development, testing, and widespread implementation of the Maternal Early Childhood Sustained Home-visiting (MECSH[®]) and Volunteer Family Connect (VFC) programs will illustrate the components and process of each type of health social science translation research (for more information about MECSH, see <http://www.earlychildhoodconnect.edu.au/home-visiting-programs/mecsh-public/about-mecsh>, and for more information about VFC, see <http://www.volunteerfamilyconnect.org.au/>).

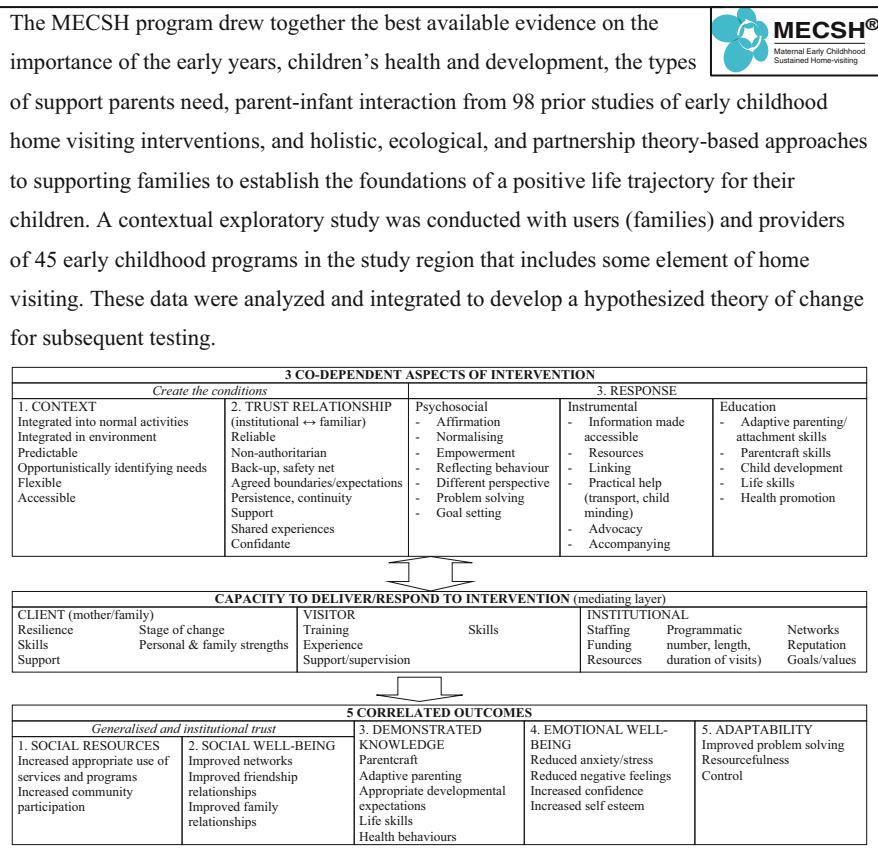
4 Translation from Basic Theory and Evidence to Human Studies

This section describes methods for T0, T1, and T2 translational research for social and behavioral intervention, which parallels the basic science and trial research for clinical interventions. Here, the focus is on providing guidance on research methods that are more appropriately used by those developing and trialing social and behavioral interventions, particularly where the context is a key component of the intervention, and both internal validity (the ability to confidently attribute outcomes to the studied intervention) and external validity (the ability to generalize the outcomes of the studied intervention to other situations and people) are important.

4.1 T0: Theoretical Research

The health social science equivalent of basic clinical research is evidence and theoretical reviews to explicate the desired outcomes and the mechanisms that will achieve them through an explicit (and testable) theory of change. Theory of change states the hypothesized links between an intervention program context, its activities and anticipated outcomes. An intervention's theory of change is grounded in a thorough understanding of the literature, both theoretical and empirical, and may also include exploratory studies where contextual understanding is needed, or there are gaps in the literature. Connell and Kubisch (cited in Blamey and Mackenzie 2007, pp. 445–446) state that:

A theory of change approach would seek the agreement from all stakeholders that, for example, activities A1, A2, and A3, if properly implemented (and with the ongoing presence of contextual factors X1, X2 and X3) should lead to outcomes O1, O2 and O3; and if these activities, contextual supports, and outcomes all occur more or less as expected, the outcomes will be attributable to the interventions.



4.2 T1: Translation to Humans

Translating the developed theory of change into an implementable and testable intervention or program involves examination and analysis of the context, participants, and actors (or potential actors) as well as logistic and infrastructure characteristics that would be needed to support any program activity that would ensue. The importance of context is well documented in research, with a number of processes proposed to analyze contexts such as stakeholder interviews, community mapping, and pilot intervention studies. In his advocacy for increased practice-based implementation research in the field of health promotion, Green (2001) makes a particular call for a rise in attention to “setting-level social contextual factors.” Green notes that if these issues were addressed in the design of programs as well as in attempts to measure and report efficacy, it would greatly advance the current quality of research and our knowledge base.

The MECSH program developers were a team of academic and clinical researchers, practitioners, and service managers, who undertook a co-design process to develop the program and document program manuals and curricula. A piloting period tested family engagement processes and practitioner competencies to implement the program as designed (Kemp et al. 2005, 2006; Kardamanidis et al. 2009).



4.3 T2: Translation to Clients


High-quality translational research should aim to ensure that intervention and programs that are provided for clients and communities are effective. Health social scientists should be encouraged to conduct comparison trials of developed interventions (the term “comparison” is used rather than “controlled” to indicate that those receiving the intervention will be compared to those not receiving the intervention, within an environment that is not “controlled”). The clinical model of randomized controlled trials with high levels of internal validity, as discussed above, however, is not a comfortable fit for many social scientists, as they attempt to control for rather than incorporate the real world (see also ► [Chap. 37, “Randomized Controlled Trials”](#)). This is the core difference between clinical efficacy and effectiveness studies, which are described by Flay (1986, p. 455) as “efficacy trials are concerned with testing whether a treatment or procedure does more good than harm when delivered under optimum conditions, effectiveness trials are concerned with testing whether a treatment does more good than harm when delivered via a real-world program.” The next sections describe some types of study designs that can incorporate internal and external validity, and quality causal comparison and context, and so are more suitable for studies of social health interventions.

4.3.1 Hybrid Research Models

Hybrid research models seek to test both efficacy and effectiveness by investigating the efficacy of an intervention in a real-world setting and/or within the context of an established service delivery system (Atkins et al. 2006). The intervention and the context are understood to be related in a reflexive process where the knowledge of how an

intervention works in the real world can help identify the efficacious components of the intervention and these components can be formulated to be effective within the real-world context (Atkins et al. 2006). Hybrid research capitalizes on the “external validity strengths of service research (e.g., ‘embeddedness’ of the study in usual care settings, with usual care clinicians) and the rigorous measurement methods developed in interventions research” (Garland et al. 2006, p. 37). This is the purposeful reflexive combination of “evidence-based practice” and “practice-based evidence” (Thase 2006; Green 2008).

Within the real-world background, most study forms that support causal conclusions can be conducted, including randomized trials, interrupted time series, wait-list/step-wedge, controlled before and after studies, and quasi-experimental designs. Designs other than those requiring individual randomization, for example, community randomization, or randomizing small groups to commence the intervention at different times (dynamic wait-list/step-wedge) can be especially important in underserved populations and low-resource settings and where it may be practically or culturally unacceptable or not feasible to individually randomize (Glasgow et al. 2005).

<p>The MECOSH study conducted a hybrid individually randomized comparison trial, with intervention delivery embedded in the established service system. Both the intervention and the control group were encouraged to use the service system, which reflexively engaged in development to accommodate the new practice intervention. The MECOSH program randomized trial simultaneously maintained a strong focus on internal validity, seeking demonstration of a clear causal pathway from the intervention to outcome through individual randomization of study participants into intervention and usual care groups while also focusing on external validity by trialing the intervention for a wide range of participants drawn from the population and delivered within the existing service system (Atkins et al. 2006; Flay et al. 2005; Hohmann and Shear 2002; Kemp and Harris, 2012). The MECOSH intervention included both practice and service system change and required that the research be conducted in a participatory way, where the researchers worked with the service managers and practitioners to develop and understand the intervention and the service context within in which it is based and to solve problems as they arose.</p>	
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4.3.2 Pragmatic Trials

Pragmatic trials are a rigorous method for assessing effectiveness, that is, the degree of beneficial effect of interventions in real-world conditions, answering the question “Does this intervention work under usual conditions?” (Thorpe et al. 2009). Godwin et al. (2003, p. 2) contend that “pragmatic trials inform practitioners and health care planners on the most clinically effective and cost effective treatments.” The Pragmatic-Explanatory Continuum Indicator Summary (PRECIS) tool was developed by Thorpe et al. (2009) to assist researchers in identifying and quantifying elements of the research design and the extent to which these reflect highly controlled or real-world conditions, distinguishing between explanatory (ideal conditions) and pragmatic (real-world conditions) trials.

The PRECIS tool consists of ten domains identified that critically distinguishing pragmatic trials from explanatory trials: (1) participant eligibility criteria, (2) flexibility of experimental intervention, (3) experimental intervention-practitioner expertise, (4) flexibility of the comparison intervention, (5) comparison intervention-practitioner expertise, (6) follow-up intensity, (7) primary trial outcome, (8) participant compliance, (9) practitioner adherence to study protocol, and (10) analysis of the primary outcome. The tool results in a “hub and spoke” or “spider map” plot where the explanatory end is central and the pragmatic end is the edge. Each spoke is a domain that is marked using a 0–4 rating scale (0 = highly explanatory, 4 = highly pragmatic). The PRECIS tool is promoted by the CONSORT Work Group on Pragmatic Trials and should become widely adopted for planning and reporting studies.

Volunteer Family Connect : A pragmatic randomized trial design for determining effectiveness of the Volunteer Family Connect program for families will be undertaken in order to provide high-quality scientific evidence. PRECIS tool for assessing varying degrees of pragmatic (effectiveness) and explanatory (efficacy) trial approaches. Wider webs represent more pragmatic trials: narrow webs represent more explanatory trials.



5 Translation of New Practices/Programs into the Clinic/Community, Health Decision-Making, and Implementation Research

Consideration of and researching the processes for translating effective programs into standard practice and population-scale implementation has recently emerged as the critical final phase of the translational research journey that starts with basic theoretical or scientific research. There are debates about whether this phase of translation is more appropriately labeled “implementation science,” but for the purposes of this chapter, the nomenclature of T3 and T4 translational research will be used.

T3 and particularly T4 translational research is an area that is still developing and requires significantly greater research investment in both clinical and social intervention research. Social science research methods are particularly important in T3 and T4 translation, regardless of whether the intervention being translated is a clinical or social/behavioral intervention. In particular, reflexive consideration of the questions of fit, reach, and feasibility of adoption and sustainability should inform the designs and processes of T0, T1, and T2 translational research.

5.1 T3: Translation to Policy and Practice

T3 translation to policy and practice describes research conducted to support policy-makers, practitioners, and health and social care decision-makers to understand, choose, and adopt effective interventions and/or programs.

Comparative effectiveness research (CER) are processes for conducting and/or synthesizing research that allow comparison of the benefits (and harms) of different interventions or programs, as they are applied to real-world settings. CER studies directly compare two or more alternative interventions, rather than comparing an intervention to a control or comparison condition, as in T2 translational research. CER can also be used to explore different ways of implementing the same intervention, for example, different service designs for delivery. Using CER processes and tools, efficacious and effective interventions, once identified and assessed, are compared and prioritized. There are a number of tools that can be used.

5.1.1 Hexagon Tool

This tool for evaluating and comparing evidence-based programs addresses six key considerations in program implementation (see Fig. 2): need, fit, evidence, readiness, resources, and capacity (Blase et al. 2013). Each key consideration is scored using a 5-point rating scale, with high-level scoring a 5, medium-level scoring a 3, and a low-level scoring a 1. Midpoints can be used and are scored as 2 or 4. Points for each evidence-based program can then be totaled and used as a means of comparison in this optional analysis.

Need refers to whether the issue being addressed is identified as significant, including social perceptions of need and data indicating need.

Fit indicates how the program aligns with agency, community, and state priorities. It also refers to how the program fits within current organizational structures and community values.

Evidence is composed of what outcomes are evidence-based, the strength of this evidence, and how effective the program is. It also includes considerations relating to population similarities.

Readiness for replication refers to whether the evidence-based program is able to be implemented as is. This involves considerations relating to operational format and expertise availability.

Resource availability requires technology and data capabilities, staffing and training, and administrative support.

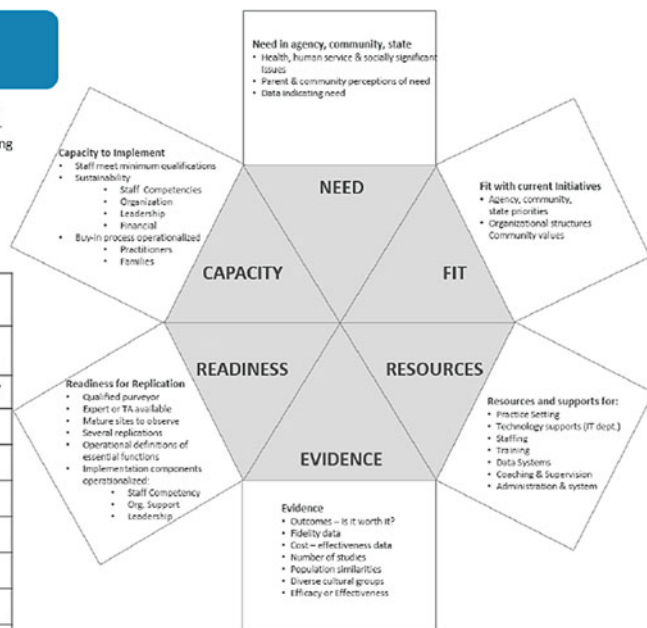
Capacity to implement refers to workforce qualifications and the sustainability of the program.

The Hexagon Tool Exploring Context

The Hexagon Tool can be used as a planning tool to evaluate evidence-based programs and practices during the Exploration Stage of Implementation.

See the Active Implementation Hub Resource Library
<http://implementation.fpg.unc.edu>

EBP:			
5 Point Rating Scale: High = 5; Medium = 3; Low = 1. Midpoints can be used and scored as a 2 or 4.			
	High	Med	Low
Need			
Fit			
Resource Availability			
Evidence			
Readiness for Replication			
Capacity to Implement			
Total Score			



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Adapted from work by Laurel J. Kiser, Michelle Zabel, Albert A. Zaslav, and Joan Smith (2007)



Fig. 2 The hexagon tool

A local district used the hexagon tool, together with a structured evidence review and cost-savings analysis, as part of a collaborative research process to assist in decision-making about new investment in programs to support vulnerable families. The district asked the questions “What could we be doing?”



Intervention	Need	Fit	Evidence*	Readiness for Replication	Resource Availability	Capacity to Implement	TOTAL
Child FIRST	5	5	4	3	1	3	21
Healthy Families America	5	4	4	5	1	1	20
MECSH	5	5	5	5	5	4	29
Minding the Baby	1	4	1	4	3	3	16
Nurse-Family Partnership	1	3	5	4	3	3	19
Parents as Teachers	5	4	1	4	4	3	21
SafeCare Augmented	5	3	2	1	2	4	17

* In this review, Evidence reflects the number of key outcomes with positive impact

5.1.2 RE-AIM Model

The Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) model (RE-AIM 2017) provides a set of guidelines to support selection and

evaluation of programs and policies designed to have a public/population health impact. The guidelines require questioning about:

- **Reach:** will/does the program reach a large and representative proportion of the target population, particularly underserved and those most in need?
- **Effectiveness:** will/does the program produce robust positive effects in the target population, with minimal negative effects?
- **Adoption:** is it feasible to implement the program in the context and in real-world and less ideal contexts?
- **Implementation:** can the program be consistently implemented with reasonable costs?
- **Maintenance:** is the program likely to support long-term and sustainable improvement?

5.1.3 Practical, Robust Implementation, and Sustainability Model (PRISM)

The Practical, Robust Implementation, and Sustainability Model (PRISM) developed by Feldstein and Glasgow (2008) guides decision-makers through systematic consideration of four elements:

- **Program (intervention):** from both an organizational perspective (including readiness, strength of evidence base, usability, and adaptability) and patient perspective (including patient centeredness and choice, service and access, and burden)
- **External environment:** including payor satisfaction, regulatory environment, and community resources
- **Implementation and sustainability infrastructure:** performance (fidelity) data, training and support, and sustainability
- **Recipients:** from both an organizational perspective (including organizational goals, management, and leadership) and patient perspective (including demographics, competing demands, and knowledge and beliefs).

5.1.4 Decision Analysis

Decision analysis with microsimulation modeling (DA) is a method that is often combined with an economic analysis to support health decision-makers to choose interventions or programs. Simulation techniques, commonly using computer modeling, are used to explore various implementation scenarios over time modeling, for example, the impacts on outcomes of differing programs, human resources and financial investment, budget constraints, and contextual and system impacts. This allows consideration of a number of “what-if” scenarios, supporting holistic and complex decision-making (Institute of Medicine 2013).

5.2 T4: Translation to Community

The final, often neglected, stage of translation is the sustainable and quality implementation of interventions or programs in the real-world, community environment.



Fig. 3 The “Fixsen triangle”

In this context, the term “community” is used to denote all those in the population for whom the intervention was designed to benefit and can refer to communities of patients, clients, or populations.

Fixsen and Blase, in their seminal works on implementation research (Fixsen et al. 2005; Bertram et al. 2015), summarize the elements needed for effective translation to community in the so-called Fixsen triangle (see Fig. 3). Two primary forms of translational research are suggested by this model: business research methods and fidelity research, both detailed below.

5.2.1 Business Research Methods

T4 translation to community research requires the extensive use of business research methods, including understanding marketing and distribution systems, organizational and leadership research, forecasting and economic analyses, and research on training and workforce and system competency to deliver interventions or programs with sustainable quality to achieve population and community outcomes. As discussed by the Institute of Medicine (2013, p. 215), this area of research is often “unassigned, underemphasized, and underfunded. If they are undertaken at all, it is usually only as one of many responsibilities of someone who may lack the training or resources to do it well.”

Figure 4 provides an overview of some of business research questions that require answering in translational research in order to promote quality and sustainable implementation of new or revised programs or policies. Such business research would intimately engage the deliverers and users of the program being translated and should

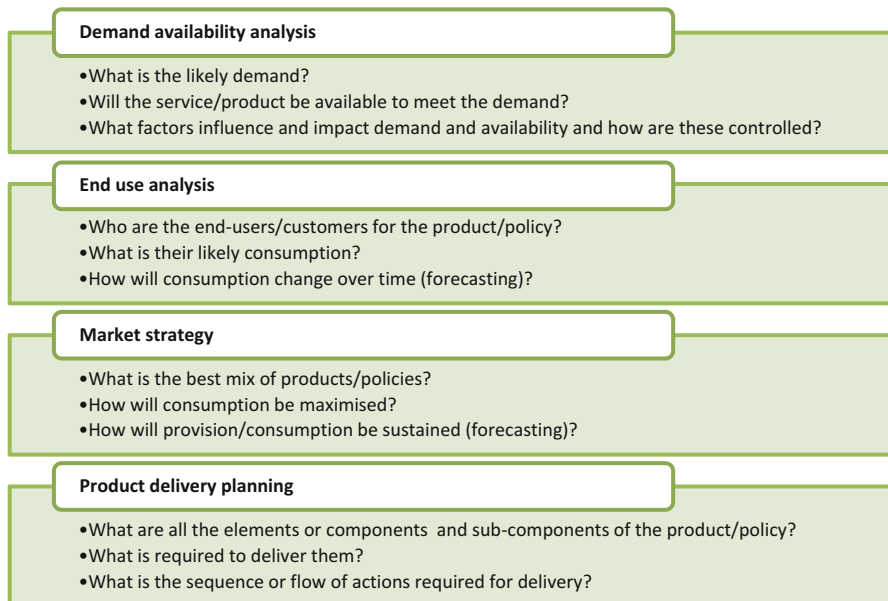


Fig. 4 Business research questions

result in practical applied knowledge arising from collaboration with practitioners and decision- and policy-makers. Research approaches and methods may include quantitative and survey methods (e.g., analysis of user data and need assessment, surveys of practitioners, training assessments), qualitative methods (e.g., policy analysis and provider and user interviews and focus groups), case studies, and, increasingly, mixed methods.

5.2.2 Fidelity Research

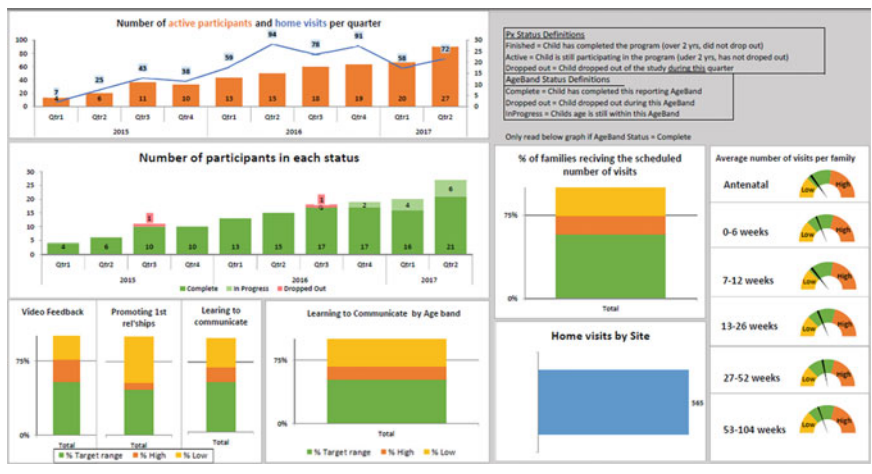
Implementation fidelity, or treatment integrity, “refers to the degree to which an intervention or programme is delivered as intended” (Carroll et al. 2007, p. 1 of 9). Achieving a balance of fidelity and adaptation is one of the key debates in implementing evidence-based programs beyond the research paradigm. Fidelity similarly defined by Mowbray et al. (2003, p. 315) as “the degree to which delivery of an intervention adheres to the protocol or program model originally developed” and adaptation, that is, modification of a program to suit a particular context (Castro et al. 2004), are generally viewed as conflicting or competing drivers (Aarons et al. 2012; US Department of Health and Human Services 2002). Regardless of the decision made about ways of managing this conflict through limiting or managing adaptation in order to maintain treatment integrity (see Kemp 2016 for a discussion of ways of managing the conflict), a structured and systematic program is needed to monitor fidelity and adaptation.

Daro and colleagues (2014) usefully describe two forms of fidelity to be monitored:

- Dynamic fidelity: adherence to the way or processes of intervention/program delivery
- Structural fidelity: adherence to the intervention/program content

The ability to identify these elements and establish appropriate performance indicators for monitoring is reflexively and inherently dependent upon the clear articulation of theory of change (T0), outcomes effected by the intervention/program (T1 and T2), and effective T3 research identifying and assuring organizational, leadership, and competency drivers of quality implementation.

The MECSH program in population-wide implementation requires that participating organizations and communities establish a sustainable data system for three-monthly monitoring fidelity against established performance indicators. They work with the MECSH International Support Service to interpret and improve performance.



6 Critical Elements of Translational Research

Across all types of translational research are a set of critical elements needed to ensure that the translation process is timely and, indeed, achieved, that is, to ensure that a greater proportion of research is translated in a shorter time frame than the 17-year average currently experienced (Morris et al. 2011). These are:

- Attention to external validity
- Understanding both whether a program/intervention is effective and why
- Collaboration and community engagement

6.1 Attention to External Validity

As noted throughout this chapter, translational of research is aided by maintaining attention to external validity throughout all research phases. In particular, researchers conducting trials in T1 and T2 translation phase should systematically consider and document:

- The community need or issue that the research is addressing and whether this is of public health concern
- The context of and participants in the study and how representative these are of the expected end-user community
- The processes and delivery components of the intervention and how replicable these are likely to be in community-based delivery
- The potential costs and benefits (and also potential negatives) of the intervention in community delivery (Green and Glasgow 2006)

6.2 Understanding Both Whether Program Effective and Why

Randomized controlled trials, both in conduct and reporting, are focused on demonstrating that the studied intervention produced the desired outcomes. Rarely are questions of “why” or how the intervention worked explored or documented. It is uncommon for specifics of intervention/program content to be published (often for commercial confidence reasons), and, even when described, disclosed detail usually reports expected content rather than content actually delivered (Gomby 2007), although more recently greater detail is being provided, aided somewhat by the phenomenon of online publication and the capacity to include greater details and appendices to journal articles. For example, the Building Blocks early childhood home-visiting trial publication in the *Lancet* included a large appendix detailing the intervention provided and reported families generally received the expected content focus as a proportion of visiting time; however, details of specific content were not provided (Robling et al. 2016).

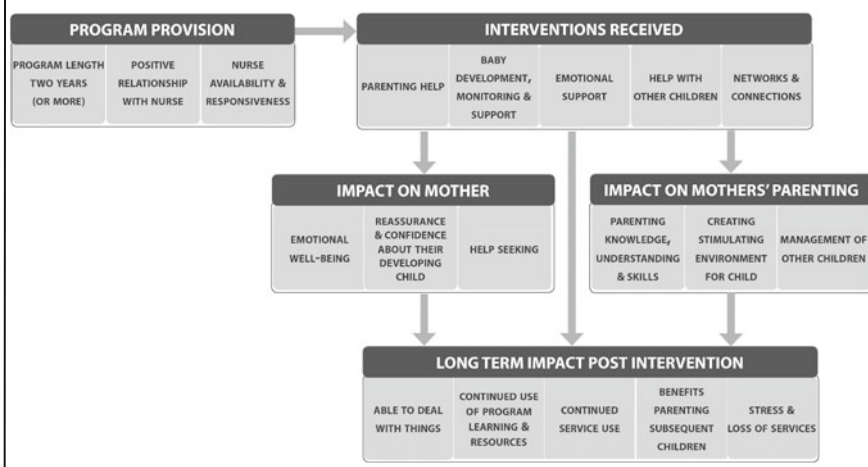
Still absent from the literature, however, is publication of the theory of change that should be developed in the T0 phase; in the absence of publication, it is not possible to know whether this is because there was no developed theory of change or a failure to publish. Where published the documentation states the expected mechanisms; rarely published is the end users’ experience or understanding of how or why the tested intervention or program worked. In the absence of such documentation, it is not possible for both those conducting the research and importantly potential community providers of the intervention to fully understand what is supposed to be happening and what actually does happen over the course of an intervention or program, and little is known about the program processes necessary for success.

Addressing this deficit in conduct and/or reporting that is inhibiting of translation requires greater use of multi-method trial designs, specifically including qualitative research exploring both the intervention/program deliverer and recipients’ understandings of the intervention and how and why it is having the impact documented. Such knowledge would considerably aid those engaged in T3 and T4 translation through documentation of:

- What the benefit of the intervention is, from both the provider and recipient perspective
- Why and how the benefit was realized
- And for whom

Such knowledge would considerably aid the “act of converting program objectives into actions, policy changes, regulation, and organization” (Green and Kreuter 2005, p. G-5).

The MECSH program has a documented program and logic model, developed using the theoretical model shown in the T0 MECSH example provided above. This model was constantly tested throughout the MECSH research, using multiple methods including qualitative research with providers and clients, and detailed quantitative data on program delivery, with such testing published throughout (see Kemp et al. 2005, 2006; Kardamanidis et al. 2009). The final testing of the model explored families’ understanding of why and how the program had longer-term benefit, using qualitative research. The families described impacts (see below) that were consistent with the program and logic model (Zapart et al. 2016).

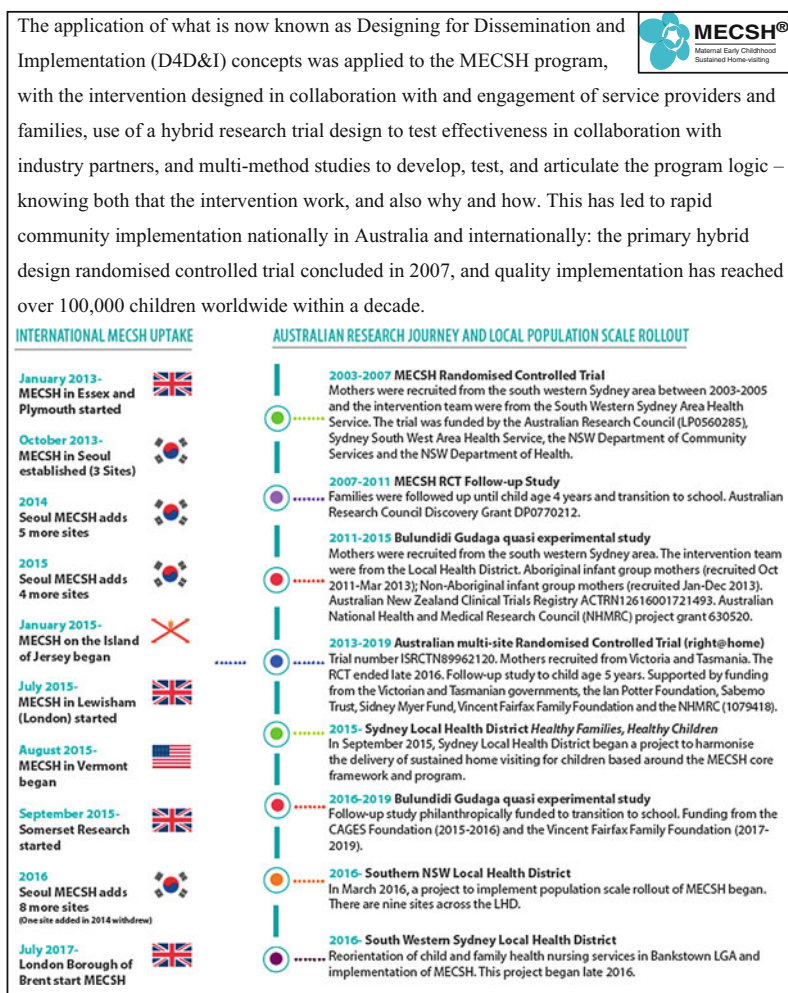


6.3 Collaboration and Community Engagement

Collaboration, with the “industry” who will be the end provider and the community who will be the end users of the intervention/program, in the design and conduct of all types of research within the translation T0–T2 pathway has the potential to significantly accelerate the translation of research findings into practice. As noted by Brownson et al. (2012, p. 192) “the importance of community and other stakeholder participation for improving the quality and relevance of research has long been acknowledged. With the growing interest in closing the ‘chasm’ between research and practice and more effectively eliminating health disparities, the potential benefits of participatory approaches for dissemination and implementation of research findings are increasingly being considered.” Industry collaboration and community engagement in all stages of research are key metrics being included in the new assessments of quality in research (Australian Government 2017).

7 Conclusion and Future Directions

There are three places for health social science in translational research. Firstly, applying the structured and rigorous T0–T4 translational research framework well developed for clinical interventions to social and behavioral interventions can result in improved interventions that are effective and implemented with quality. Secondly, the use of health social science research methods throughout all phases of translation can improve the “translatability” and speed of translation of both clinical and social/behavioral interventions. The concept of Designing for Dissemination and Implementation (D4D&I) captures the idea that consideration of the end users’ requirements (both provider and community) should be integral to all phases of intervention/program development and trials. Finally, T3 and T4 translation phases are predominantly conducted through the use of social science methods, supporting healthcare decision-making and high-quality community-scale implementation.



Health social science is critical to increasing the likelihood of and rapidity with which interventions/programs are successfully disseminated and implemented, as discussed throughout this chapter, and evidenced in the MECSH and VFC program examples throughout. Future use of the parallel translation science framework for social/behavioral interventions, and increased use of social science methods in all types of translational research, will ensure that the focus of research effort is increasingly on community impact.

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Qualitative Interviewing

23

Sally Nathan, Christy Newman, and Kari Lancaster

Contents

1	Introduction	392
2	Why Use Qualitative Interviewing?	393
3	Planning for Interviews	400
3.1	Sampling or Selecting Participants to Interview	400
3.2	Recruitment, Access, and Ethics	402
3.3	Planning and Piloting Your Approach	402
4	Doing Interviews	403
4.1	Interview Practice: Listening, Questioning, and Probing	404
4.2	After the Interview	407
5	Conclusion and Future Directions	408
	References	409

Abstract

Qualitative interviewing is a foundational method in qualitative research and is widely used in health research and the social sciences. Both qualitative semi-structured and in-depth unstructured interviews use verbal communication, mostly in face-to-face interactions, to collect data about the attitudes, beliefs, and experiences of participants. Interviews are an accessible, often affordable, and effective method to understand the socially situated world of research participants. The approach is typically informed by an interpretive framework where the data collected is not viewed as evidence of the truth or reality of a

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situation or experience but rather a context-bound subjective insight from the participants. The researcher needs to be open to new insights and to privilege the participant's experience in data collection. The data from qualitative interviews is not generalizable, but its exploratory nature permits the collection of rich data which can answer questions about which little is already known. This chapter introduces the reader to qualitative interviewing, the range of traditions within which interviewing is utilized as a method, and highlights the advantages and some of the challenges and misconceptions in its application. The chapter also provides practical guidance on planning and conducting interview studies. Three case examples are presented to highlight the benefits and risks in the use of interviewing with different participants, providing situated insights as well as advice about how to go about learning to interview if you are a novice.

Keywords

In-depth interviews · Semi-structured interviews · Qualitative interviewing · Interview study design · Interview methodology · Interview method

1 Introduction

Interviewing is often described as the “foundational” method of qualitative research, with good reason (Liamputtong 2013). Using verbal communication and face-to-face conversation as a means to share our experiences and views of the world around us is fundamental to human social life (Serry and Liamputtong 2017). With a strong grounding in the social convention of conversation, then, interviewing offers an accessible and effective mechanism for accessing the socially situated life worlds of individuals and groups and recording a rich source of knowledge on the distinctive views and perspectives of our informants (Braun and Clarke 2013).

However, there is an art and a science to qualitative interviewing which risks being underestimated by this representation of the interview as an “intuitive” social process. Therefore, this chapter aims to introduce the novice interviewer to the range of benefits, challenges, and strategies that we have learned which are associated with qualitative interviewing in our work as social researchers in various areas of health and medicine. We have deliberately imagined a reader who is new to qualitative interviewing, but has a fairly robust understanding of the complexities of methodological decisions, and is fuelled by a curiosity about what is possible to be achieved through interviewing methods.

The chapter is divided into sections which discuss what qualitative interviewing can offer as a research method, how to effectively plan for an interview, and how to conduct the interview well, to achieve the best possible experience and outcome for both interviewer and participant. These are accompanied by three case studies, which draw on our own experiences in using qualitative interviewing in our work, which provide more situated insights into the challenges and the rewards of using this method.

2 Why Use Qualitative Interviewing?

Qualitative interviewing is employed today as a primary method across the social and health sciences and in many other related fields (Minichiello et al. 2008). But why is this the case? While interviewing can also be used to collect quantitative data, with the researcher using a structured tool which limits answers, what exactly are the benefits and limitations of using interviewing for qualitative analysis (Bryman 2016)? The simplest answer is that qualitative interviewing permits us to broaden or extend our understanding of what is known about a specific set of issues or experiences (Silverman 2017). Qualitative interviewing is, therefore, typically informed by an interpretive research framework which does not view the accounts provided by research participants as evidence of truth or reality nor as generalizable beyond the specific context in which they are originally provided (Crotty 1998). Instead, qualitative interviewing aims to curate historically and culturally specific insights into how the subjective experience of a unique social world is viewed and how those perspectives come to be knowable in particular ways (Davies 2007).

In most contexts, a key principle which underpins the use of interviewing is an interest in capturing the “richness” and “breadth” of perspectives on the topic of interest, which supports the use of techniques which prioritize open-endedness and open-mindedness (Braun and Clarke 2013). By this, we mean that interviewing is best employed as an exploratory research method for answering questions which hold few, if any, prior assumptions about the views and experiences that participants will share. Researchers must remain genuinely open to being surprised by what they hear and to be willing to actively pursue further insights from participants regarding the subject under investigation. Indeed, attempting to understand the viewpoint of the participant is critical to this method, both in terms of understanding the purpose and in conducting interviews well.

There are distinctive traditions within interviewing practice and key differences between these (Punch 2005; Bryman 2016). For example, in the *oral history interviewing* tradition, the aim is to document personal accounts to build a picture of the lived experience of important or under-recognized moments in history. These interviews are usually not recorded anonymously, as the accuracy of the account is essential to the history-recording aims of the method. In the *in-depth interviewing* tradition, the researcher is very “hands-off,” sometimes commencing the interview with only one question and building the interview around the stories the participant shares, rather than any predetermined topics. Finally, in the *semi-structured interviewing* tradition, arguably the most common approach, there is a balance between the interests of the researcher and participant, with the questions moving across a range of topic domains, but still permitting the interviewer to remain responsive and flexible in asking further questions about emerging topics and stories (see Serry and Liamputtong 2017).

Across these distinctive approaches, there are shared advantages and disadvantages of qualitative interviewing methods (Bryman 2016). Focusing first on the advantages, we know that qualitative interviewing is valuable for exploring topics on which there is little known, or when the issues are particularly complex, given

they can be used to pursue a deep understanding of an issue. We also know qualitative interviewing works well as a flexible and responsive method which can be adapted to suit each context and conditions and the needs and preferences of individual participants. Because the emphasis is placed on understanding how participants give meaning to their experiences, this flexibility also increases the likelihood of achieving the quality and depth of perspective that is sought through this method.

There are also practical advantages of using qualitative interviewing (see next section), which holds appeal for researchers operating in constrained resource environments. Interviewing is a relatively cheap method to employ, with costs mainly focused on employing skilled interviewers, reimbursing participants for time and costs and translating audio recordings into analyzable transcripts. Minimal specialist equipment is required, and even novice researchers can conduct a quality interview, once they have a good understanding of the key principles and practices (see “[Case Study 1: Learning How to Interview – Christy Newman](#)”). Finally, there are many advantages to using interviews to capture the perspectives of people who have experienced disempowerment or marginalization or who, due to physical illness or disability, may have difficulty participating in other types of research. Interviews can be conducted in people’s homes or other “safe” spaces, and if confidential, participants should be reassured that their courage in sharing their stories will be justified by the care and attention paid by ethical researchers to the research process and to really recognizing and learning from the participant’s account.

Case Study 1: Learning How to Interview – Christy Newman

As a qualitative social researcher, interviewing represents both the everyday stuff, and the greatest reward, of my work. I have conducted over 200 interviews myself, exploring a wide range of experiences relating to health, sexuality, and relationships, with an incredibly diverse range of people. I have also had the opportunity to “teach” interviewing skills at both the undergraduate and doctoral student levels, including preparing junior and doctoral researchers to record over 300 of their own qualitative interviews. I am also the Editor in Chief of a journal which publishes health sociology from around the world, and we receive manuscripts reporting data collected in the form of qualitative interviews more than any other method. These opportunities have led me to reach a number of conclusions about the exceptional breadth of affordances and complications associated with putting this method into practice and the key traps that novices need to keep in mind when learning how to interview.

The first challenge is to learn how to prepare interview guides and practices which will support the novice interviewer to both answer the research question and remain flexible and responsive to what comes up during the exchange with

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Case Study 1: Learning How to Interview – Christy Newman (continued)

a research participant. The idea of an “open question” is familiar to most, but it holds a particular meaning in the context of a research interview. Learning how to craft an interview question so that it avoids permitting a yes/no answer, but also directs the participant toward the issues and ideas you are interested in exploring, can take quite some work. Learning from experienced researchers is helpful, but finding your own, unique way of posing questions can probably only be developed through trial and error. You need to learn how to feel alright with sounding a little bit stupid when you have to ask repeated follow-up questions, or sit with an awkward silence, without jumping in or moving on as we would in a social relationship.

The second challenge builds on these complexities by requiring skilled interviewers to learn how to juggle multiple priorities in the moment. Not only must you proficiently manage the technical dimensions of an interview – recording equipment, sound quality, pace, and timing – you must also attend to maintaining a meaningful and sustained rapport with the participant through eye contact, body language, verbal reassurance, and responsiveness to changing needs and preferences. Adding in the challenge of staying focused on the topic, while also pursuing unexpected leads, means novice interviewers can feel they are being asked to learn something as complex as circular breathing! Students who have had the opportunity to practice interviewing in my courses almost always confess that they had expected this skill to be more “intuitive” and felt quite discomforted by how difficult they found it in reality. Nonetheless, with practice and attention to becoming more proficient with each of these dimensions, it is possible to relax into the experience and really start to enjoy the intensive interaction that a research interview makes possible.

The third trial in learning how to interview relates to managing your post-interview responsibilities. Students can often find it difficult to know how to record their observations of the interview experience, in the form of field notes or reflexive comments, and can benefit from reading a range of examples of the kind of sensory, interpersonal, ethical, and empirical observations which they should ideally be seeking to capture. Transcribing and deidentifying are always shockingly time consuming for students, who were unaware how many choices are available to them in translating the spoken word into a usable form of written text. Nonetheless, gaining these experiences is essential to becoming a good interviewer, because it is only when you work with the final version of a qualitative interview transcript that you understand what you are aiming to achieve from the beginning.

My approach to supporting others in learning how to interview is to try to convey the incredible complexity and privilege that can come from engaging in this method. There is an incredible sense of intimacy, generosity, and connection that you can achieve in many one-to-one interviews, which is not

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Case Study 1: Learning How to Interview – Christy Newman (continued)

something I've experienced as much with other methods. As you become more senior in the academic world, there is an expectation that one will increasingly delegate research tasks such as interviewing to others. But personally, this aspect of my work is one of the most rewarding, and I hope very much to be able to be interviewing people for the rest of my working life.

However, there are also a range of limitations of interviewing, and some inherent challenges and complexities which mean this method needs to be carefully appraised before employing. The most important issue to resolve is whether you want to know what people actually do, rather than what they *say* they do. Interviews capture an account of an experience, attitudes, or a view or feeling but cannot document practices and behaviors in everyday life, as do observational methods, for example. Another potential limitation relates to the accuracy of people's accounts. Even if participants believe they are providing you with a "true" recollection of an event or experience, all memory is shaped by cognition, culture, and context. There is a very clear – albeit often unconscious – motivation to present a more socially acceptable account in the context of research than may be ideal for answering some questions, particularly when exploring sensitive or taboo subjects. Suggets refer to "[Case Study 2: Interviewing the Unenthusiastic – Sally Nathan](#)". This has added complexities when interviewing "up," given there may be additional reasons for someone in a position of power to manage their position carefully, even in a confidential interview (see ► [Chap. 126, "Researching Among Elites"](#)). As a related point, given qualitative interviewing aims to achieve depth and insight from participants, the expectations of the interviewer may need to be tempered when working with people for whom this way of thinking or speaking is not familiar or easy (see "[Case Study 3: Interviewing "Elites" – Kari Lancaster](#)").

Case Study 2: Interviewing the Unenthusiastic – Sally Nathan

In-depth interviews are commonly used in research with "vulnerable groups" and about sensitive topics, such as people's drug taking behaviors, and the experience of traumatic events, such as domestic violence. Vulnerable groups can be those whose behavior, experience, or power in society may make them more at risk of harm from research (Liamputtong 2007). They can sometimes also be less than enthusiastic about your research study as their life priorities, such as finding a home, or a job, or just getting through the day are more pressing.

As with all research, these participants must be given assurances that their identity will be protected. Researching sensitive topics and with vulnerable groups using in-depth interviews, however, requires extra vigilance. The slow

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Case Study 2: Interviewing the Unenthusiastic – Sally Nathan (continued)

building of trust and rapport which often underlies the consent process for vulnerable participants may mean more time in the field to become known to the participants (Foster et al. 2010).

A major group of participants I have been doing research with for more than a decade are young people aged 13–18 years in residential drug and alcohol treatment (Foster et al. 2010; Nathan et al. 2011). This body of research has been focused on examining young people's experiences of treatment and related services, and their life pathways, before and after treatment. Unsurprisingly, they are sometimes less than enthusiastic about many parts of the process. First is having another person ask them questions. They have already been asked questions by counselors, maybe also the police, and family and community services. They are also wary of signing forms and some have poor literacy. Then recording them can be the final straw. One young person turned the recording device on and off every few minutes as if it was admissible in court. Another said more at the end of the interview as we were walking back to the service, but the recording device was off, and the passing traffic would have made it impossible to capture the audio. Sometimes a young person will say yes to participating, but they are not really engaged. They do not want to share very much about themselves and answer in one-word responses despite open-ended questions and probing for more depth.

Together with my team, we have worked hard to get the most from the interviews we do with young people using a variety of strategies. We have trialed many locations. We have trained a peer interviewer who now comes to many of the interviews with another member of the team. She shares about her experiences briefly at the beginning and as appropriate, during the interview. It becomes more of a three-way conversation, and the data we collect is often a co-creation of meaning between us as a small group but focused on the young person's experiences. It is not necessarily "the truth," but the approach we have taken has yielded rich and interesting data, and the process seems to be more comfortable for the young person. There is a participation continuum in in-depth interviews from being neutral to active as an interviewer, and my stance in this and related studies has often lent toward the latter.

In our interviews, we have also strived to come from a strength-based perspective, not just problematize their lives. However, we have found the participants were not used to saying anything "good" about themselves. The sharing by the peer interviewer often opened up this discussion about what was good in their life. We have also trialed ways to move beyond talk using more participatory methods, such as drawing, and this is an important approach to consider in researching with young people.

In reviewing the data we have collected, we are asking what we are finding: Are they performing an "identity" (Rhodes et al. 2010; Riessman 1993) for us

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Case Study 2: Interviewing the Unenthusiastic – Sally Nathan (continued)

as a research team, whether consciously or unconsciously? Is social desirability a factor at play? For example, some young people may not want to admit to certain practices, like injecting or using “ice” or crystal methamphetamine due to stigma. Alternatively, they may “drug rave” and overstate their drug and alcohol using practices.

Despite its challenges, working with this group of young people is revealing and rewarding. Sometimes, we are the first people who have asked them about their lives without judgment or to provide treatment. We do, however, need to question what is the data we are collecting and what can it tell us to make a material difference to the lives of these young people.

Case Study 3: Interviewing “Elites” – Kari Lancaster

When we think about using interviewing methods in the health social sciences, we often think about the complexities of research involving vulnerable participants with lived experience of disease, trauma, or disability or studying sensitive topics like sexuality, terminal illness, or mental health. There has been a focus in the method literature on how to manage issues of confidentiality, anonymity, and power dynamics to ensure that vulnerable participants are appropriately protected, respected, and not placed at risk of harm. However, notions of “vulnerability” and “power” are not always straightforward nor are “patients” the only kinds of participants we might encounter.

In my research, I have studied health policy processes in the highly politicized domains of illicit drug use and blood-borne virus transmission. This research has involved interviewing government policy-makers, clinicians, professors, experts, as well as advocates holding senior roles in non-government organizations. These participants are by no means people we would ordinarily think of as “vulnerable.” In many cases, they occupied important public positions and possessed decades of professional experience and knowledge. They were educated, articulate, and had a good understanding of research. But, in my experience, assumptions about what constitutes “vulnerability” and “power” can get us into trouble. We need to be careful in approaching every interview encounter.

There is a body of literature which has grappled with the issues associated with interviewing “up” or interviewing “elite” participants (e.g., Lancaster 2017; Morris 2009; Neal and McLaughlin 2009; Ostrander 1995). Some scholars suggest that “elite” participants may be difficult to recruit because their professional positions create barriers to researcher access. Others argue that “elite” participants might seek to exert too much control over the interview

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Case Study 3: Interviewing “Elites” – Kari Lancaster (continued)

process or that it may be difficult for the interviewer to develop rapport, especially if the interviewer is younger, female, relatively junior in status, or inexperienced in corporate culture. This literature emphasizes that “elite” participants are “used to being in charge, and they are used to having others defer to them” (Ostrander 1995, p. 143). What is striking is the way that “power” is seen as fixed and given, which leaves little room to better understand the vulnerabilities of participants usually seen as “elite” and consider how these might play out in interviews.

It is important to challenge the idea that certain participants are “in possession” of power, while others are necessarily always already “vulnerable” (Lancaster 2017). “Elite” participants are not a homogenous group, and thinking of them as such obscures crucial differences and the fact that every interview encounter depends on context and a process of co-production between the interviewer and the participant. Seeing power dynamics as fixed (as assumptions about the category of “elite” participants tends to do) limits discussion about how else we might think about and be responsive to encounters with various kinds of participants (Neal and McLaughlin 2009) and the ways such dynamics will shift and change.

Despite their “elite” status, in my experience interviewing policy-makers, clinicians, and other professional experts, there are a range of vulnerabilities and sensitivities which must be considered. Issues of anonymity and confidentiality are complex to overcome when small sampling frames are used, especially when the individuals involved occupy public positions. Moreover, participants might know each other through ongoing work and collaborations and discuss the study between them. Being attuned to these particular challenges is important so as not to expose participants to risk of harm such as retaliation from others involved in political processes, potential job loss, or, indeed, compromising the ongoing viability of policies and programs. While these may not be the kinds of concerns usually associated with protecting “vulnerable” participants, these sensitivities needed to be managed, and participants reassured to maintain trust throughout the study. However, these are not easy choices to make. Choosing not to report sensitive material or “keeping secrets” (Baez 2002) can help produce and perpetuate problematic power dynamics and, therefore, must be seen as a political choice which shapes the interview data and research process.

The major practical drawback of interviewing is that this method can be time consuming, particularly when researchers reach the stages of transcription and data analysis. In addition, while the method is teachable, as are all research methods, some of the more “intuitive” aspects of good interviewing practice require both aptitude and experience to execute them well (see “[Case Study 1: Learning How to Interview – Christy Newman](#)”). A genuine rapport with the research participant is

crucial but can be quite difficult to achieve in some contexts (see “[Case Study 2: Interviewing the Unenthusiastic – Sally Nathan](#)”, and “[Case Study 3: Interviewing “Elites” – Kari Lancaster](#)”). Researchers need to be willing and able to reflect on their own personal and social backgrounds to understand how they are shaping the interaction and how they may come to figure in the interview data. Nonetheless, with preparation, reflection, and practice, anyone with a genuine interest in understanding the experiences of others can learn how to employ, and to love, qualitative interviewing methods.

3 Planning for Interviews

As we intend to make this chapter more practical to students and novice researchers, we will use the first person in our discussions in this and following sections. Once you have decided that qualitative interviews will enable the study to collect the kind of data you need to answer your research questions, the next step is to plan and design the project to ensure it is achievable within the available timeframe and resources. However, when planning a qualitative study of any type, the researcher must be open to the reality that their research plan may need to be adapted in the field. Being flexible in your approach is not only acceptable but often necessary, to ensure rich data is collected that answers the research questions (Braun et al. 2017; Patton 2015).

The reasons that what you actually do in the field may differ from what was planned are many and varied. The researcher may be able to predict some of these potential changes in the planning stages, but many of them cannot be predicted. For example, you may have overestimated the number of participants that can be recruited, or you may need to recruit them differently than planned.

In planning, the researcher needs to address question such as: Who should I interview? What questions do I want to ask them? How will I recruit them? Where will I conduct the interviews? How will I record the conversation? What ethical issues need to be considered? Each of these questions requires attention to the nature of the method and reasons for choosing interviews (see Sect. 2). Importantly, your research questions should be a central consideration in the planning of an interview study. In short, good planning will increase the likelihood firstly that the study will obtain ethics approval and secondly that you will collect rich and informative data to fully answer the research questions. Interview studies with limited planning often result in “thin” data which does not provide novel insights to the field of inquiry.

3.1 Sampling or Selecting Participants to Interview

When selecting participants for interview, the researcher may choose many characteristics that need to be included in the sample, depending on the objectives of

the research. For example, a researcher may decide to study participants of an age, gender, location (city or country), profession, ethnicity, health status, and so on. The researcher needs to decide what characteristics might matter in the experiences or for the phenomenon that is the focus of the study. Deciding who will be interviewed and why is best answered by thinking back again to the study research questions. Sample size is often much less important than the “make-up” of the sample (Ritchie 2001).

Sometimes it is useful to begin with maximum variety sampling (Liamputtong 2013; Patton 2015), gathering data from a range of different people, such as, in a study of homelessness, or to focus in on one particular group, such as young people who are homeless. The researcher may also hone in on a group following initial interviews. Give yourself time to review and listen to early interviews to inform the sample composition and shape the direction of later interviews (see section on “Doing Interviews”).

Different approaches to selecting participants are often called sampling frames (Liamputtong 2013; Patton 2015). These are usually divided according to probability and non-probability sampling. “Logic of probability” sampling is common to quantitative research to permit generalization to population, whereas “logic of non-probability” or purposive sampling is to select information-rich cases for in-depth understanding not generalization (Liamputtong 2013; Patton 2015). Snowball sampling, where participants suggest someone else to interview, is also common in interview studies, particularly with more hidden populations, such as sex workers (Liamputtong 2013). The number of participants is usually not large in a qualitative interview study, but the depth of the data and the time with each participant is likely to be long. The most important principle is to ensure that the data collected is sufficient to answer the research question and provide something of value to the field, such as a new way of thinking about a problem or issue. This can often only be determined in the field. It is also important to ensure, as much as possible, that the research fairly tries to explore the range of views of your chosen participant group or is transparent about the views it does and does not explore (Glaser and Strauss 1967).

There is no magical number for an interview study; it is topic and context dependent. There are good qualitative studies with only a few participants and some with 30 or more. A common term in the method literature is “saturation” (Mays and Pope 2000; O’Reilly and Parker 2013). The term originated in grounded theory research but has now become increasingly employed to justify sample size across diverse paradigms, unfortunately as though it can stand as a measurable marker of adequacy (O’Reilly and Parker 2013). This concept of “saturation” is often used uncritically as a shortcut way to explain sample size, with many authors stating “data were collected until no new themes emerged.” This use of the term is highly problematic. Transparency about how sampling was undertaken (and why) is a far better marker of sample size adequacy for a particular study than the use of the blanket term “saturation” (Liamputtong 2013; O’Reilly and Parker 2013).

3.2 Recruitment, Access, and Ethics

Working out how you will gain access to participants is a key question to ask at the planning stage and includes a range of ethical and consent considerations. Many ethics committees require “arms-length” recruitment (National Health and Medical Research Council 2007), that is, someone other than the researcher being involved in inviting the participants to be part of the study so that they do not feel “coerced” to participate. This can be easier said than done. Sometimes it is less ethical to have a clinician, for example, recruit patients for a study, as the patient may feel more coerced by their treating clinician than an unknown “researcher.” Recruitment requires careful planning to be both feasible and ethical (see ► Chap. 5, “Recruitment of Research Participants”). Confidentiality and informed consent also need to be addressed, as well as procedures to prevent potential harmful consequences to participants (see ► Chap. 106, “Ethics and Research with Indigenous Peoples”).

Think carefully about the timing (day and time) of interviews to ensure they will be most suitable for participants and the expected duration of the interview. Face-to-face interviews are the most common and are more likely to help establish rapport (Bryman 2016), but phone and video interviews are also options to consider if participants are geographically spread (Irvine 2011). Also consider whether the interview needs to occur after an event, such as following discharge from hospital. Where to conduct the interview is the next consideration. It needs to be somewhere that is comfortable for the participant but also where you can capture the conversation without too much background noise. Interviewing someone in their home is an option in some studies, but issues relating to the safety of the interviewer need to be carefully managed. You also may decide you are not the most suitable person to conduct the interviews, and a peer interviewer can be trained to assist (see “Case Study 2: Interviewing the Unenthusiastic – Sally Nathan”).

3.3 Planning and Piloting Your Approach

In-depth interviews are usually very unstructured, and sometimes can consist of only one question, followed by probes to explore issues of relevance to answer your research questions (Gillham 2000; Hesse-Biber and Leavy 2011) (for further discussion of probes, see section below). Semi-structured interviews usually involve the development of an interview guide. This involves developing and planning questions in advance, and, on the whole, similar wording will be used when asking questions of different participants (Bryman 2016). Although the questions or topics for discussion are planned in advance using the interview guide, the interviewer should still be flexible and responsive, giving the participant plenty of freedom and scope to respond, asking additional questions that pick up on ideas introduced by the participant and should not rigidly following the order of the questions prepared (Bryman 2016). Thinking about not only the topic or content of the interview but also different styles of questions is important when constructing an interview guide. For example, introductory or opening questions should allow

the participant to respond at great length, get them talking, and help the researcher to understand better what participants *themselves* see as important in relation to the topic being studied (Serry and Liamputtong 2017, p. 44). Other types of questions, like structuring questions, can help redirect the focus of the interview and assist the participant to move on to a new line of questioning, helping to close off the previous discussion (Serry and Liamputtong 2017, p. 45) (for more discussion of questioning, see section below).

As discussed earlier, qualitative interviews are focused on the participant's frame of meaning and their worldview, so the interviewer is often led by the issues of relevance to the participant addressed in their response to the opening question. Nonetheless, the interviewer needs to keep in mind the aims of the research and steer the participant back to the topic of the study if things go offtrack. Probing is, therefore, a critical tool to employ in in-depth interviewing (see next section for discussion of probing questions). Piloting for in-depth interviewing is, therefore, a bit more difficult than in other types of interviews, such as semi-structured, as the way an interview unfolds will be participant dependent. However, test out the opening question and possible probes with colleagues or someone from the participant group if feasible. A key learning from many years of interview research by the chapter authors is the importance of getting to concrete examples or experiences by asking the participant to tell a story or give a more specific account, to move the participant beyond generalities, such as "I really felt let down." Key questions generally relevant to most studies are:

- Can you tell me more about that incident?
- Can you tell me about a specific time that you felt like that?
- Do you have a story about <topic> that stands out as important?

Even if you have only a few questions to pilot, the use of audio or video recording equipment requires practice. Coming back from an interview that was rich and rewarding to find nothing on the recording device is a researcher's worst nightmare and more common than you may think. Choose a recording method appropriate to the participants and context. Methods could include written field notes or electronic recording with audio or video devices. If the interviewer will be doing the interviews on their own, then practicing the skill of using the equipment and note-taking while remaining focused on the participant and encouraging them to tell their story as well as keeping to time is essential.

4 Doing Interviews

Having selected participants for recruitment, arranged access, piloted the approach, and planned your interview questions, you are ready to enter the field and start your interviews. There is no single right way to conduct a qualitative interview (Kvale 2007; Minichiello et al. 2008). As we noted earlier, the key to a good interview is often the ability to be adaptive and responsive to socio-political contexts and the

needs of individual participants. Depending upon the epistemological, ontological, and methodological commitments of the study, the interviewer may see her role as gathering and documenting a rich account of the participant's knowledge, experiences or thoughts on a topic, or, alternatively, see herself as an active participant in the co-construction of such accounts or subject positions. We concur with Minichiello et al. (2008) that "the interview is neither an objective nor subjective method but that its essence is *inter-subjective interaction*" (Minichiello et al. 2008, p. 78). It is from this standpoint that we provide some general guidance for thinking about how to successfully engage in the interview process and for developing techniques and skills.

4.1 Interview Practice: Listening, Questioning, and Probing

Conducting successful interviews involves practical elements such as good planning and preparation, as well as interpersonal elements such as rapport. Good interviewing practice, therefore, requires the development of a range of skills and attributes. Building on Kvale's (1996) criteria, Bryman (2016) outlines key elements for successful interviewing. The interviewer must be *knowledgeable* (familiar with the interview's topic and prepared), use *structuring* throughout (to give purpose and direction to the interview), be *clear* (ask simple, understandable questions), be *gentle* (give participants time to think and allow for silences), be *sensitive* (listen attentively and empathetically), be *open* (remaining flexible and responsive to the participant's interests and emphasis), employ *steering* (to get to what they want to discover), stay *critical* (being prepared to challenge participant's inconsistencies), *remember* what has been said, *interpret* (clarify and extend what a participant says), maintain *balance* between saying too much or too little (directing the interview while allowing for flexibility and not exerting too much control), and, finally, be *ethically sensitive* to ethical aspects of interviewing (including confidentiality and anonymity). Underpinning this comprehensive list are a number of key qualities to be fostered: listening, flexibility, and nonjudgment (Bryman 2016).

While interviewing is much more complex than an everyday conversation, the interviewer must also work to help the participant feel relaxed and comfortable and ensure a conversational social interaction. Listening, building rapport, and styles of questioning will all contribute to this dynamic.

An interviewer's listening skills are crucially important. Minichiello et al. (2008) describe different modes of listening including *listening analytically* and *listening as support and recognition*. Maintaining concentration and focus throughout the interview is essential. While it might sound simplistic, it is important to enter an interview feeling refreshed and not tired or socially drained. This might mean planning space and time before and after an interview and not conducting multiple interviews back-to-back in one sitting, especially if the research involves talking about sensitive or difficult subjects. Being alert and listening attentively to the participant's language, emotions, attitudes, inferences, arguments, perceptions, ideas, obfuscation, contradictions, and needs throughout the interview, while simultaneously maintaining

balance and control over the direction and structure of the interview, and internally beginning the process of analytic interpretation, is a juggling task which requires energy, focus, and presence.

As an intersubjective interaction, a good interview requires the building of trust between the interviewer and the participant (Johnson 2001). *Rapport* is a term often used when discussing this aspect of interviewing technique, but it is rarely defined with any specificity. Minichiello et al. (2008, p. 82) helpfully describe this process as generating “a *productive interpersonal climate*.” Building rapport requires more than the innate social skills of the interviewer. Like all aspects of interviewing, it is important to develop the skills required to be actively involved and present in the interaction. Rapport is about interpersonal interaction but also relates to ethical sensitivity. Building rapport involves ensuring that the participant is comfortable and at ease in your company. This involves both verbal and body language. Eye contact is important, as is being observant of both your own body language and the participant’s. If a participant’s body language changes, this might be an indication that they are anxious about responding to questions or have become aware of something in the interview environment which is causing them discomfort. Maintaining open body language, smiling and offering verbal reassurance through “listening noises” can put the participant at ease and communicate that you are interested in what they have to say, encouraging in-depth responses to questions rather than closing them off.

Rapport is also an important consideration when thinking about the order in which you will ask questions of the participant. Starting with easier, open-ended questions will help to get the participant talking and comfortable, before you approach more sensitive or difficult topics.

How you approach the process of asking questions will in some ways depend on the study design, the chosen style of interview, and preparation and piloting of the interview guide (see earlier section). Despite the possible variability in interviewing styles, in qualitative interviewing, there are a few general principles to consider in relation to questioning technique. Whether you are using a semi-structured interview guide or a more open-ended in-depth interviewing approach, you will need to be responsive and flexible, pursuing different lines of enquiry and drawing out detail from the participant. Kvale (1996) and Bryman (2016) categorize different types of questions: introducing questions, follow-up questions, specifying questions, direct questions, indirect questions, structuring questions, silence, interpreting questions, and probing questions (to which we shall return below) (see also Serry and Liamputtong 2017, pp. 44–45, for a helpful list of question types). When asking questions of your participant, it is important to give them time to reflect and respond and answer in their own way. Do not jump in to silences, but rather practice being comfortable in them and giving the participant space to think and speak. When formulating questions, it is important that they are worded in such a way that they elicit open-ended and not closed (or yes/no) responses. The way that questions are asked should generally be neutral and nonjudgmental. The question should not anticipate any response or position. Never assume you know what the participant’s view or experience might be, and try to avoid offering examples which might shape

the participant's response or reveal your own assumptions about a topic. It is also important that questions are clear and simple, rather than rolling multiple questions into one (Rubin and Rubin 2012).

The interview guide will guide the shape, substance and structure of the main interview questions or topics, but these questions will also be supplemented with follow-up questions and probes to ensure a successful interview. Probes "help regulate the length of answers and degree of detail, clarify unclear sentences or phrases, fill in missing steps, and keeping the conversation on topic" (Rubin and Rubin 2012, p. 164). Being skilled in these questioning techniques can help the interviewer to remain flexible and be confident when moving away from the structure of the interview guide and generate a richer understanding of what the participant is saying. Rubin and Rubin (2012) describe different types of probing questions. *Continuation* probes encourage the participant to keep talking about the topic without necessarily knowing what will be said next ("And then what happened?"). *Elaboration* probes are slightly different in that they ask the participant for more detail about something which has already been said ("Can you tell more about that?"). *Attention* probes signal that you are interested and will also encourage elaboration ("That's interesting"). *Clarification* probes resolve ambiguity or ask the participant to explain something you found confusing ("Would you mind saying that again? I am sorry I didn't quite follow.") *Steering* probes can be used to bring the conversation back to the topic of concern, if the interview has diverged down a different path. Probes can also be used in anticipation of interpretation and analysis, for example, seeking *evidence* to determine what may be more important or using *sequence* probes to clarify the order of events. Of course, not all probes are verbal questions. A smile or a nod, a hand gesture, or leaning forward in anticipation of a detailed answer will demonstrate to the participant that you are interested in hearing more, whereas a confused or quizzical look may encourage a participant to elaborate or clarify their meaning.

In addition to being attentive to what is being said, and listening analytically, the interviewer must also maintain focus on the pragmatic aspects of the interview process throughout. How much time is left? Have all the topic areas or questions been covered? Is the recording device on and working throughout the interview? Is the space still comfortable – temperature, air flow, noise, and privacy? How can the interview be wrapped up well at the end in such a way that the interview feels complete and the participant is happy to conclude? Both verbal and nonverbal cues can also be used to close the interview well and signal to the participant that the process is coming to an end. It is important that the interviewer allows plenty of time to end the interview and that it is not closed off abruptly. Giving the participant an opportunity to add further thoughts and reflection and wind down the process can be done by saying "I think we've come to the end of my questions," "You've given me a lot to think about," or "We're almost out of time" or asking questions like "Is there anything you like to add?" Positioning the participant as the expert in the research can also help end the interview positively and generate final reflections, for example: "Is there anything else that you think might be helpful for us to think about?" "Have I missed anything?" Never turn the recording device off prematurely. It is often at this point of winding down the interview that participants will have more to say. At the end of

the interview, thank the participant for their time, and when leaving the interview setting, be warm and respectful of the fact that this has been an intimate social interaction. Ending the interview well is a particularly important consideration for studies which involve follow-up interviews. The number of contacts you have with participants will depend on your study design but also has implications for the interview process. A one-off interview may enable people to reveal sensitive experiences more readily as they may feel more “anonymous” in the process. On the other hand, multiple interviews may help build trust and rapport which may assist in gaining a deeper understanding of someone’s experience but may lead to boundary blurring for the researcher and difficulties in ending the research and leaving the field (Dickson-Swift et al. 2008).

4.2 After the Interview

Keeping a research diary (or recording what are called “field notes”) is an important practice that can help the interviewer process the interaction which has just taken place and assist later with data analysis. After each interview, spend some time writing notes to record your insights. This can also be done via an audio recording soon after the interview and later transcribed as field notes. It is best to record reflections as soon as possible after you complete the interview, so your recollection of the interview is fresh. These notes should cover analytic, practical, and personal elements. Reflect on your own role as an interviewer: How did the interview go? What went well and what could be improved in your approach? Could you have probed differently at points? What happened that could have been handled differently? Did the participant raise issues or perspectives you had not yet thought about in this study? If so, is there anything that you need to follow up in your reading or raise with participants in subsequent interviews? On a practical level, make some notes about the participant and the setting where the interview took place. What was the participant wearing? Was the setting noisy and busy or quiet and comfortable? Were you interrupted? Did you have any technological problems that need to be resolved before your next interview? Are there other things to follow up? This process can form the basis of an audit trail and promote reflexivity, both essential to rigor in qualitative research. An audit trail is a clear account of the research process and includes documentation of steps taken, for example, how access was gained, how mistakes and surprises were addressed, and how data were collected. Reflexivity is about documenting and reflecting on how your beliefs and values, and who you are as a person, such as your sex, age, and other characteristics, including any shared experience with your participants, may have impacted on their interaction with you in the interview. Reflexivity also comes into play when you are making meaning or interpreting your data in analysis.

As you finish the interview and leave the field with your digital recording in hand, there are a range of important analytic and ethical choices to be made regarding data preparation (McLellan et al. 2003). Analysis, coding, and considerations related to transcription and data management need to be considered (see ► [Chaps. 47,](#)

“Content Analysis: Using Critical Realism to Extend Its Utility,” and ► 48, “Thematic Analysis”).

In applying for ethics and planning your study, it is important to think about how findings will be fed back participants. Checking the data or account collected with the participant is sometimes advocated in qualitative research texts and “quality criteria” and is often called *member checking* (Tong et al. 2007). Planning to send transcripts to participants can be useful in checking that someone’s experience has not been misrepresented but can also be problematic in that it assumes that data collected are “truth,” whereas it is a time-situated telling of experience. It also assumes that the participant has the time and is interested in seeing the transcript. If member checking is employed, the participant seeing this “telling” in black and white at another time may result in significant changes to the transcript or challenges regarding “control” over data (see “Case Study 2: Interviewing the Unenthusiastic – Sally Nathan”). Importantly, no study uses all the data in every transcript, and this is another reason to consider an alternative approach. Another option can be to feedback a summary of key issues raised in the interview or across a number of interviews to see if there is anything the participant would like to add to the issues raised. This could even become a second interview for further data collection. This approach is more about building a shared understanding of the findings and relates to the idea of co-construction of meaning. Presenting back to a group of participants and having a discussion is another way to feedback findings and again collect further data to inform your research.

5 Conclusion and Future Directions

In this chapter, we have reviewed what we see as the key issues to be resolved before using qualitative interviewing as a research method, to ensure they are anticipated and addressed during and after the interview is conducted. We hope this is both illuminating of the complexities involved in this method and encouraging for novice interviewers who have much to gain from immersing themselves in learning how to become a good interviewer. To conclude, we want to emphasize that we see qualitative interviewing as both complex and teachable, both intuitive and rule-bound, and it is these contradictions which add to the richness and surprise inherent in this method. Braun and Clarke (2013, p. 80) have so beautifully described in their description of the experience of the interviewer:

A qualitative interviewer is not a robot, precisely programmed to conduct every interview according to a set of inviolate rules. Rather, a qualitative interviewer is a human being, with a distinctive personal style, who uses their social skills, and flexibly draws on (and in some cases, disregards) guidance on good interview practice to conduct an interview that is appropriate to the needs and demands of the research question and methodological approach, the context of the interview and the individual participant.

While there is already a substantial methodological literature on interviewing, this quote also points to one of the future directions we see emerging in this field: the role

of digital technologies in qualitative interviewing practice. As discussed, interviews can be recorded online, as well as in person, but the increasing opportunities to record interviews virtually are likely to reveal a whole new range of issues associated with the quality, ethics, and security of digital interviewing (Braun et al. 2017). In addition, there is an increasing recognition of the value of participatory and arts-based methods in research (Leavy 2015), and many issues to be examined regarding how interviewing might support and be challenged by these explicitly co-constituted approaches to research practice.

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Narrative Research

24

Kayi Ntinda

Contents

1	Introduction	412
2	Narrative Research: Definition and Scope	413
2.1	Relational Narrative	413
2.2	Lived Narrative	414
2.3	Narrative Therapy	414
2.4	Autobiographical Narrative	414
3	Narrative Research as a Methodological Framework	415
3.1	Data Collection	416
3.2	Narrative Analysis	416
3.3	Narrative Interpretation	417
4	Applications to Health and Social Sciences Research	418
5	Advantages and Disadvantages of Narrative Research	419
6	Conclusion and Future Directions	420
	References	421

Abstract

Narrative research aims to unravel consequential stories of people's lives as told by them in their own words and worlds. In the context of the health, social sciences, and education, narrative research is both a data gathering and interpretive or analytical framework. It meets these twin goals admirably by having people make sense of their lived health and well-being in their social context as they understand it, including their self-belief-oriented stories. Narrative research falls within the realm of social constructivism or the philosophy that people's lived stories capture the complexities and nuanced understanding of their

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significant experiences. This chapter presents a brief overview of the narrative research approaches as forms of inquiry based on storytelling and premised on the truth value of the stories to best represent the teller's life world. The chapter also discusses data collection, analysis, and presentation utilizing narrative analysis. In doing so, this chapter provides illustrative examples applying narrative-oriented approaches to research in the health and social sciences. The chapter concludes by outlining the importance of narrative research to person-centric investigations in which the teller-informant view matters to the resulting body of knowledge.

Keywords

Collaboration · Lived experience · Intersubjectivity · Life world · Narrative inquiry · Storytelling · Meaning-making

1 Introduction

Narrative research or inquiry is one of the more recent qualitative methodologies that focuses on life stories as the essence of people-oriented sciences. As a research inquiry, narrative approaches endeavor to attend to the ways in which a story is constructed, for whom and why, as well as the cultural discourses that it draws upon (Bochner 2007; Trahar 2009). Narrative research is based on the premise that people understand and give meaning to their lives through the stories they tell (Andrews et al. 2013; McMullen and Braithwaite 2013). In doing so, people utilize narratives to compose and order their life experiences. Through the use of story forms, people account for and give meaning or significance to their lives (Bleakley 2000).

Among the early proponents of narrative research include Connelly and Clandinin (1990) who proposed to put the person back to the center of research inquiry ensuring that people's voices are not lost in translation. The two main elements comprising this approach are participants' account of a particular experience and the exploration of meaning embedded in the participants' stories. The focus on particular experiences is from the presumption that lives are bounded by events which vary in significance to the people involved. Exploration of personal meaning refers to the fact that meanings are evolving and persons may recognize some meanings and not others.

Narrative research is increasingly used in studies of health, education, and social sciences practice for its unique value to representing social phenomena in its full richness and complexity as well as providing a particularly generative source of knowledge about meaning individuals ascribe in their daily social contexts (Clandinin and Connelly 2000; Riessman 2008; Clandinin et al. 2009; Clandinin 2013). Richness and complexity are from the multiple layers of meanings people impute to their life worlds. Generativity of knowledge is from how constructing a meaning leads to new and deeper meanings than at the start. There is a growing interest and utilization of narrative research among the social science-related disciplines and also for its benefit in sensemaking, communication, learning/change,

identity and identification (Errante 2000; Rhodes and Brown 2005; Atkinson and Delamont 2006; Spector-Mersel 2010) as discussed below.

The chapter considers narrative research as both a data collection and interpretive or analytical framework to understand people's sensemaking and life choices. First, the chapter begins with definitions of narrative research and when narrative research can be used. Next, the chapter presents types of approaches to data collection, analysis, and interpretation in the narrative research tradition. In this regard, this chapter presents and discusses illustrative examples of use of narrative research in the health and social sciences. Finally, the chapter concludes with suggestions for importance of narrative research in health sciences and future directions.

2 Narrative Research: Definition and Scope

As previously noted, narrative research (also referred to as narrative analysis) is a family of approaches which focus on the stories that people use to understand and describe aspects of their lives from the stories they tell (Riessman and Quinney 2005; Kim and Latta 2009). The term "narrative" carries multiple meanings and is used in a variety of ways by different human or social science disciplines. It is mostly used synonymously with "storytelling," although a distinction is made by some researchers between narrative as an account by an individual of their own experience and storytelling as it is related by others. Narrative research allows for comprehending, describing, and acting within the frame of the storyteller experiences; the story is how we make sense of the world (Clandinin and Connelly 2000). Several types of narrative inquiry have been proposed: relational, lived, therapy, and autobiographical.

2.1 Relational Narrative

This refers to shared intersubjectivity between the researcher and participant for understanding of the phenomena under study based on their construction of meanings authentically (Murphy and Aquino-Russell 2008). Relational narrative may be useful in the discipline of nursing to assist individuals who experience health inequalities to clarify their values, and, in becoming more fully their authentic selves, community members who typically feel powerless in the public space may act with confidence in influencing the distribution of healthcare resources. For example, Gadow (1999) indicates that in engagement in a relational narrative or intersubjectivity, nurses may be present to patients as they clarify their values and, therefore, transform experiences of disease and suffering into experiences of personal development. Relational narrative has been utilized for understanding response to treatment by patients attending nursing care. For example, Tsianakas et al. (2012) explored the relative value of surveys and detailed patient narratives in identifying priorities for improving breast cancer services as part of quality improvement process. In this case, patients' narratives revealed "relational" aspects of patient

experience. Those identified by the survey typically related to more “functional” aspects and were not always sufficiently detailed to identify specific improvement actions. Patients’ experiences have become central to assessing the performance of healthcare systems globally and are increasingly being used to inform quality improvement processes of which relational narrative is ideally suited.

2.2 Lived Narrative

This type of narrative seeks to engage participants through telling stories about their lived lives with no presumptions about the importance of specific experiences (Connelly and Clandinin 2006). The typical characteristic common in lived narrative inquiry is negotiating into the relationships, research purposes, transitions, and how researcher and participants are going to be useful in those relationships. For instance, Jeon et al. (2010) reported the findings of a systematic narrative review of qualitative studies concerning people’s experience of living with chronic heart failure, aiming to develop a wide-ranging understanding of what is known about the patient experiences. The review identified the most prominent impacts of chronic heart failure on a person’s everyday life including social isolation, living in fear, and losing a sense of control. Thus, lived narratives have been identified as a common strategy through which, for example, patients with chronic heart failure can manage their illness through sharing experiences and burdens with others.

2.3 Narrative Therapy

This is used in counseling and psychology premised on the fact that mental health healing is a personal matter and with unique meanings constructed around people’s everyday lives. Narrative therapy is based on the construct that there is no single “truth” (Nwoye 2006). For instance, Heidari et al. (2016) and Kim and Park (2017) explored the effectiveness of narrative therapy as a person-centered therapy on happiness and death anxiety of elderly people and on people with dementia. Findings revealed that person-centered narrative therapy has a positive effect on increasing happiness and reducing death anxiety. Findings also indicated that person-centered narrative therapy can reduce agitation, neuropsychiatric symptoms, and depression and improve the quality of life. As a therapy, retelling narratives enable people to create new meanings to get rid of disabling stories harmful to their happiness.

2.4 Autobiographical Narrative

This refers to a special form of narrative inquiry which seeks to understand people’s stories as autobiographies within a cultural context (Bruner 2004). For instance, Appel and Papaikonomou (2013) explored how three culturally diverse South African women constructed death and bereavement. The three diverse cultures

were Tswana, Islamic Muslim, and Afrikaans. The themes of “mourning procedures and practices,” “bereavement behavior,” “sociopolitical context,” and “private and public display of grief” were identified as valuable areas for clinical practice and future research. Likewise, Wood et al. (2006) explored the narratives of older children in their teens, who have experienced parental AIDS-related illness and death in six cities in Zimbabwe. Findings indicate that, even though many orphaned teenagers desire direct communication with adults about parental illness and death, adults themselves, whether the sick parent, other relatives in the household, or a caregiver following parental loss, are often ill-equipped to identify and manage children’s distress positively. Research data generated by autobiographical interviews are usually regarded and analyzed as monological narratives drawn from autobiographical memory of the participants as shown above. If one specific style of narrative research catches the researcher’s interest, then the research ought to focus on the discipline-based literature to guide their research efforts.

3 Narrative Research as a Methodological Framework

As a methodological framework, narrative research is defined by the following three aspects: temporality, sociality, and place (Connelly and Clandinin 2006; Clandinin and Huber in press). Temporality, sociality, and place stipulate the three elements of inquiry and serve as a conceptual framework. Elements are dimensions which need to be concurrently explored in conducting narrative inquiry. Temporality refers to events under study which are in temporal transition (Connelly and Clandinin 2006). Focusing attention temporally leads researchers toward the past, present, and future of people, places, and events under study. It is important to attend to temporality in narrative inquiry as quality of experience through time is viewed as narrative.

Sociality entails paying attention to both personal and social conditions by narrative researchers. Personal conditions involve “feelings, hopes, desires, aesthetic reaction and moral disposition of the inquirer and participants” (Connelly and Clandinin 2006, p. 480). Social conditions refer to conditions under which people’s experiences and events are taking place. These social conditions are typically understood in a way through culture, social, and language narratives (Craig and Huber 2007). The relationship between the researcher and participant’s lives is another aspect that is important to observe under narrative research as the researcher cannot detach him/herself from the inquiry relationship.

Place is about the specific concrete, physical, and topological boundaries of place where the inquiry and events take place (Connelly and Clandinin 2006, p. 480). Of essence to observe under this element or commonplace is that all events take place some place (Connelly and Clandinin 2006). Connelly and Clandinin (1990) contend that experience is narratively constructed and narratively lived in the research process. An important characteristic of narrative inquiry or research rests in a view of the research process as relational. During the research process, the researcher and participant work collaboratively in constructing meaning of the phenomena as experienced by the participant and researcher. Meaning is constructed through

negotiation and collaboration between the participant and the researcher (Clandinin and Connelly 2000). According to Clandinin and Huber ([in press](#)), attending to experience through inquiry in all three elements is, somewhat, what differentiates narrative inquiry from other methodologies. Attending to the commonplaces or elements allows for narrative inquirers to study the complexity of relational composition of people's lived experiences both inside and outside of an inquiry.

The importance of attending to all three elements is very critical in narrative research. Clandinin and Connelly's (2000) framework for narrative research highlights three specific conditions of experience: interaction, continuity, and situation. Experience is perceived as involving people in relationship with others and their environment. They indicate that for an individual to be able to comprehend experience, the individual ought to consider the personal, social, and temporal elements of experience and also the context in which experience takes place (Connelly and Clandinin 2006).

3.1 Data Collection

There are various methods of data collection that can be utilized in narrative research as the researcher and participants enter into a collaborative partnership. Data can be collected in many forms such as autobiographical writing, documents such as class plans and bulletins, journals, field notes, interview transcripts, observations, storytelling, letter writing, pictures, metaphors, and personal philosophies. However, most narrative studies commonly use interviews as a key research tool (see also ► [Chap. 23, "Qualitative Interviewing"](#)). Data are transcribed, and then transcripts of these interviews are made available to the participant for further discussions, and these form part of the narrative record. The participant then interprets his or her own biography as a series of causal, meaningful events. Journals kept by participants also form a source of data in narrative research. Data gathered are analyzed through narrative analysis with the aim to provide evidence from experience described (Kim 2006; Clandinin and Rosiek 2007).

3.2 Narrative Analysis

Narrative analysis refers to a number of procedures for interpreting of the narratives generated in research: formal structural and functional (Clandinin and Connelly 2000; Frank 2002; Ellis and Bochner 2005). Formal structural means of analysis entails exploring how a story is structured, how it is developed, and where the story starts and ends. Functional analysis focuses on what the narrative is "doing" or what is being conveyed in the story (e.g., moral tale or a success story) (Freeman 2007; Clandinin and Huber [in press](#)). In the analysis of the narrative, the researcher tracks sequences, chronology, stories, or processes in the data, acknowledging that most narratives have backward and forward nature that ought to be unraveled in the analysis (Creswell 2012; Zulu and Munro 2017). Narrative meaning is transferred

at different levels (for instance, textual level that is suitable for hermeneutic analysis, informational content level that is ideal for content analysis, or interpersonal level that could be subjected to conversational analysis).

Furthermore, narrative analysis has its own methodology which entails analysis of data in search for individual narrative accounts by the researcher (mainly have to do with commonalities in and across texts), narrative threads (core emerging themes), and temporal/spatial themes (present and future contexts) (see also ► [Chap. 49, “Narrative Analysis”](#)).

3.3 Narrative Interpretation

Narrative interpretation is concerned with meaning-making and construction. It seeks to understand social action in which people attach subjective meaning (Crotty 1998; Currie 2010). In narrative interpretation as meaning-making, knowledge and meaning are acts of understanding people’s lives on their own terms (Herman 2009; Caracciolo 2012). For instance, narrative interpretation entails exploring why narratives carry the meanings they do in the social, cultural, economic, and political context in which they are produced. That is when the application of social theory is necessary in that it takes into consideration the wider context of the reality presented. In order to achieve the intersubjective understanding of narratives, digital technologies can be used as a contemporary channel of communication that can support but cannot exclusively reproduce the social context in which the research occurs. The use of different tools to record participants’ narratives can enhance the credibility of narrative research interpretation (see ► [Chap. 2, “Qualitative Inquiry”](#)). It can enable for suitability of dialogue with the research participants during extended periods of time and, thus, allow for cross-checking for consistency of participant’s accounts during different platforms in which they interact with the researcher.

Narrative interpretation seeks to go behind and inside data to identify hidden meanings and not just accepting data at face value. The ordering is critical to the narrative interpretation, and whether it is genuinely a time ordering or not is less critical. Scientific examples of this ordering issue abound (Denzin and Lincoln 2000; Cochran 2007). It is important to study all data in order to obtain a complete picture.

Data analysis in narrative research includes four stages: (1) preparing the data, (2) identifying basic units of data, (3) organizing data, and (4) interpretation of data as suggested by Newby (2014). Preparing the data entails grouping it in a form that can be manipulated. Identifying basic units of data involves categorization procedure as categories of significance to the research issue are constructed and named. Organizing data is a chronological procedure in which associations between units are built, evaluated, and maybe rejected for the whole procedure to start again. This grouping of data can be done at different levels. Basic data units are aggregated into first-level groupings and first level to second level and so on as long as the data and interpretation permit it. Interpretation of data is about aggregating data into meaningful groupings as interpretation or from implicit understanding. For instance, Ntinda (2012) sought to unravel conceptions of ability aspects among educational

consumers using a narrative approach. Findings indicated people's narratives in areas of assessment domains: learning readiness, aptitude, personal development, community norms, socialization, and guidance and counseling. The study also provided an opportunity for participants and researchers to co-construct knowledge disconcerting the power dynamics between outside experts and local community insiders about appropriate support for Botswana school learners by providing critical aspects of ability they perceived learners needed support in.

4 Applications to Health and Social Sciences Research

In recent years, there has been an increasing interest in narrative ways of knowing, resulting in a rise in using narrative research methods and techniques (Clandinin and Rosiek 2007; Riessman 2008; Spector-Mersel 2010). Even though narrative research has long tradition in disciplines such as anthropology, counseling, history, and psychology (Connelly and Clandinin 2006), the turn to narrative in health is relatively new. Narrative research has been used in health to help researchers understand patients, medical personnel-patient relationships, or other issues such as personal identity and culture. Health and healthcare issues can be expressed through the narrative process (Wang and Geale 2015).

The concept of narrative inquiry was first utilized by Connelly and Clandinin (1990) as an approach to describe personal stories of teachers. Clandinin and Connelly's (2000) approach to narrative research is rooted in Dewey's philosophy of experience. Thus narrative inquiry is a means of "understanding and inquiring in to experiences through collaboration between the researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin and Connelly 2000, p. 20). Every individual has his or her own story, and some research studies are designed to collect and analyze the stories of participants (e.g., when we study the experiences of parents of children with schizophrenia). Similarly, narrative research can be used to enhance teaching and learning for students and educators in health and social science-related disciplines. This has been through placing experiences of students and educators at the center of curriculum development. Stories are at the core of narrative analysis, whether the stories be of illness (Frank 2000), stories of participants in programs (Gibson 2012), or stories of students (Wang 2017). How to make sense of stories and, more specifically, the texts that tell the stories is at the core of narrative research.

The study on the effects of narrative career facilitation on the personal growth of a disadvantaged student is an example of using narrative research application (Maree et al. 2010). It emerged from researcher's desires to share career story of a gifted 20-year-old, male student from a poor economic background called Lebo, an undergraduate student from South Africa enrolled in education. Narrative career facilitation starts when the facilitator creates a safe atmosphere within which the client, which is being respected throughout, is invited to tell his/her story (Eloff 2002). Stories do not only simply describe a person's life but also compose one's view of oneself as a human being. The stories that are told eventually become a

person's frame of himself/herself (Eloff 2002). The concept of his motivation to study was challenging for researchers and allowed for more critical investigation.

As you can see, I have always been dictated and motivated learner. I always wanted to study further and get a good job so I can take care of myself and my family. I knew from an early age that I was clever and that I could do it. [Lebo] (Maree et al. 2010, p. 408)

This response was very important in helping the researchers make meaning of the motivation for Lebo to study education. Following the intervention, the student evidenced an improved future perspective and a more positive academic self-image. The process of narrative career facilitation had a positive effect on the overall personal growth of the student.

Ngazimbi et al. (2008), in their article, "Counseling caregivers of families affected by HIV/AIDS: The use of narrative therapy," assert that narrative therapy has a potential to enhance counseling interventions with African caregivers who are caring for family members diagnosed with HIV/AIDS. A caregiver may tell a counselor that caring for a member diagnosed with HIV/AIDS is challenging because the community believe that the infected person is immoral (which is related to the stigma associated with HIV/AIDS). Even though the client might not necessarily agree with this assumption, he or she does not challenge it. In this case, the caregiver is not mentally healthy due to the inability to challenge what society says about caring for people living with HIV/AIDS. Thus, narratives have also be utilized to understand vulnerability among carers of people living with HIV and AIDS and have indicated improvement in the quality of life of the carers with regard to burden of care, isolation, and stigma.

5 Advantages and Disadvantages of Narrative Research

Advantages of narrative research include the following: it is easy in getting people to tell their story, it gains in-depth data, participants are willing to reveal self and account reflection, the revelation of truth, and the provision of a voice for participants (Creswell 2012; Newby 2014). In using narrative research, it is fairly easy to get people to tell stories, since most people are usually pleased to share a story about themselves and one wants to report their story. Gaining in-depth data (thick description) is possible since this often occurs with ease in narrated events. In using the narrative approach to present findings, researchers can access rich strata of information that give a more in-depth understanding of the specifics of the participants' viewpoints. The knowledge gained from narrative research can provide the reader with a detailed understanding of the subject matter and further insight on how to apply the stories to their own context (Savin-Baden and Niekirk 2007). Moreover, individuals have a habit of not hiding truths when telling stories, or if they attempt to, it mostly becomes obvious in thorough data interpretation. In carrying out narrative studies, researchers form a close bond with participants where participants may feel that their stories are heard and important (Creswell 2012). Furthermore, the approach allows for bridging the gap between research and practice.

The disadvantages of narrative therapy include the difficulty of establishing the role one assumes in the inquiry. For example, Ellis and Bochner (2000) assert that if one is a storyteller rather than a story analyst, then their goal becomes therapeutic rather than analytic. This role is usually difficult to negotiate in narrative research. Stories can be challenging to understand in terms of the relationship between the storytelling in the interview and story-making in the presentation of data. It is often difficult to decide the relationship between the narrative account, the interpretation, and the retold story. The negotiations of data interpretation and presentation of data can be problematic.

Also setting boundaries to stories can be difficult in five aspects: (1) who authors the account (e.g., the researcher or the participant), (2) the scope of the narrative (e.g., an entire life or an episode of life), (3) who provides the story, (4) the kind of conceptual framework that has influenced the study (e.g., critical or constructivist), (5) and whether or not all these elements are included in one narrative.

6 Conclusion and Future Directions

Even though narrative research shares features of other qualitative research approaches such as the social focus in ethnography and the focus on experience in phenomenology, it is the simultaneous exploration of all the three elements: temporality, sociality, and place that shape and make narrative research/inquiry. Experience can be narratively created and narratively lived. The distinctive feature of narrative research is dependent on the view of the research process as relational. Narrative inquiry is collaborative and informant centered. Meaning is constructed through negotiation and collaboration between the participant and the researcher. The narrative research design adopted for health science studies provides opportunities to probe deeply into complexities surrounding health-related research. Narrative research is not simple storytelling; it is a method of inquiry that uses storytelling to uncover nuances around people's lived experiences. The process of storytelling, a key element in narrative research, provides the opportunity for dialogue and reflection, each intertwined and cyclical. The narrative approach can be adopted for health-related studies as it provides a unique opportunity to explore researcher/participant relationship over time in health sciences and to place health in the context of participants' lives. Employing a specific narrative research approach requires close attention to the "fit" of the research question/context with the particular method under consideration: relational, lived, therapy, and autobiographical. While sharing some narrative commonalities, each of the various methods enables the emergence of unique analytic and interpretive perspectives about stories relevant to health research and practice.

With advances in word-recording softwares, narrative research will become a mainstay approach from easy access to construct personal and experiential stories with reliable systematic scoring making for greater confidence in research findings and their transportability in that data will be more objectively analyzed so as not to only rely on subjective interpretation of researchers. Narrative research will also

continue to present as a useful tool for empowerment which is important for social construction of reality from the perspective of participants. In the discipline of health, for instance, patients' experiences will continue to be essential to assessing the performance of healthcare systems worldwide and are increasingly being utilized to inform quality improvement processes of which relational narrative is particularly appropriate. There is a growing need for research on person-centered narrative therapy which is a holistic and integrative approach designed to maintain well-being and quality of life for people with mental and health issues, as it includes the elements of care, the individual, the carers, and the family for which narrative research is ideally suited.

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The Life History Interview

25

Erin Jessee

Contents

1	Introduction	426
2	Approaching the Life History Interview: Preliminary Considerations	428
3	Conducting Life History Interviews: Best Practices	430
4	After the Interview: Analyzing and Disseminating Life History Interviews	435
5	Conclusion and Future Directions	438
	References	439

Abstract

In this chapter, I explore the “best practices” and core values with which researchers should align when conducting life history interviews to elicit information about an individual’s past and present lived experiences. Drawing primarily on literature from the multidisciplinary field of oral history, I outline the process of determining in which circumstances life history interviews might be beneficial for addressing a research question and how life history interviews are typically designed, conducted, and analyzed. I also examine the challenges that can arise when conducting life history interviews, particularly when investigating sensitive subject matter or working in conflict-affected settings, for example. In the process, I reflect on over a decade of fieldwork in post-genocide Rwanda and Bosnia, wherein discussions of the past are often highly politicized and researcher fatigue – particularly related to the recent atrocities – is common. This provides a starting point for discussing how the best practices for life history interviewing may need to be adapted to ensure that they remain culturally and politically appropriate in different settings. Taken together, the chapter provides readers

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425

with a foundation for deciding where life history interviews might enhance their research, and how to adapt current best practices on life history interviewing to suit their research needs and maintain a high ethnic standard in their fieldwork when documenting intimate details about participants' lives.

Keywords

Life history · Interview · Ethics · Methodology · Intersubjectivity · Memory

1 Introduction

The *life history interview* – a common means of documenting an individual's account of their life – is one of several types of interviews used by scholars and practitioners from a range of disciplinary backgrounds (Yow 2014). As a methodology, it is valued for its ability to amplify individual actors' voices and privilege their insights on historical events in tandem with those of the researcher and other relevant sources. For this reason, practitioners stress that the life history interview is distinct from the autobiographical narrative and other related methods aimed at revealing people's lived experiences (see ► Chaps. 23, "Qualitative Interviewing," ► 24, "Narrative Research," and ► 30, "Autoethnography"). The interviewer's presence, and their efforts to guide the interviewee's reflections, however minimal, as well as the interviewer's efforts to bring the resulting narrative into conversation with a broader body of academic literature, mean that practitioners understand the life history interview to be a co-creation between the interviewee and the interviewer. Oral historians refer to this collaborative process as *sharing authority* – "a complex, demanding process of social and self discovery" (Frisch 1990, p. 112) based on "a reimagination of the past that is being shared in a joint moment between the narrator and interviewer" (Abrams 2016, p. 27). As such, practitioners do not typically regard the life history interview as an objective source of information about the past. Instead, they engage with its subjective and intersubjective nature to explore the meaning that past has for an individual at a particular moment in time and what this can tell us the production of historical knowledge surrounding a given topic. Thus, they approach the narratives they elicit with a critical eye (as should always be the case when working with oral or written sources), anticipating that it will encapsulate a blend of fact and fiction that is unique to the narrator and the time when the interview was conducted (see, e.g., Passerini 1979, 2007; Portelli 2016; Lummis 1988; Abrams 2016).

For these reasons, the life history interview is arguably best suited to those research questions where a comprehensive understanding of an interviewee's subjective worldview is desirable. Life history narratives are particularly beneficial for revealing "the tangle of relations" and symbiotic interactions that exist between an individual's memories and those memories that circulate in the broader cultural circuit in which individuals are embedded – referred to most commonly as *collective memory* (Basu 2011, p. 33; see also, Summerfield 2004). It can facilitate a more nuanced understanding of how public and private

narratives of a historical event can evolve over time in response to a range of personal, political, cultural, and social factors, resulting in selective remembering and forgetting that greatly shapes what people know and understand about the past, alongside their lived experiences of past events. And the reverse is also true. As people try to make sense of their past experiences by sharing their stories publicly, their narratives can also gradually influence what the broader public holds understands to be “true” about historical events and actors. By understanding this symbiotic relationship and its impact on personal and collective understandings of the past, practitioners can – in the spirit of renowned anthropologist Michel-Rolph Trouillot (1995) – offer insights on the production of history under different governments and within different communities, for example, as well as at different points in time.

Despite these potential strengths, however, the life history interview is not without complications and potential pitfalls. Of particular importance, life history interviews can be quite time-consuming and often involve long-term engagements with participants and their communities that over time can pose challenges for researchers and their analysis, as well as for participants. This is particularly true when working in crisis- or conflict-affected communities, among other highly politicized research settings, as well as with people whose memories may have been impacted by traumatic or distressing experiences or whose narratives the researcher finds repellent (see, e.g., Blee 1993; Thomson 2010; Adler et al. 2011; Jessee 2011; Field 2012; Cave 2016). Similarly, the commonly cited “best practices” for life history interviewing often need to be adapted to address the specific needs of individual researchers and participants, as well as the specific cultural and political contexts in which the interviews will occur (Jessee 2017a). For these reasons, researchers and practitioners should carefully consider whether life history interviews are personally, culturally, and politically appropriate for their research projects, and in instances where they decide to proceed, revisit their ethical and methodological frameworks throughout their fieldwork, and adapt their methodology as necessary to ensure it remains safe and ethical for the people and communities with whom they are working (see also ► Chaps. 106, “Ethics and Research with Indigenous Peoples,” and ► 108, “Ethical Issues in Cultural Research on Human Development”).

In the following sections, I will discuss how to determine whether life history interviews might be appropriate for a given research project. I will then outline the core values and practices that practitioners should use as a starting point for their research. Having covered the basic principles of life history interviewing, I will then reflect on a decade of experience conducting life history interviews in Rwanda and Bosnia to illuminate the potential pitfalls of this particular method and highlight the need for careful, ongoing adaptation of our best practices as our research progresses. In doing so, I will draw primarily upon literature from the multidisciplinary field of oral history, within which the life history is but one type of interview that practitioners may use. Taken together, the chapter will provide readers with a foundation for maintaining high ethnic standards in their fieldwork when documenting intimate details about interviewees’ lives and their insights about the past and present.

2 Approaching the Life History Interview: Preliminary Considerations

In considering whether the life history interview might be appropriate methodology to employ for a research project, a good starting point is to consider whether the project might benefit from the wealth of data and insight that can emerge from engaging with people's firsthand experiences and inherited memories. Early practitioners recognized that the life history interview can be essential for developing an understanding of historical events and actors that consists not just of factual statements but also the narrator's "memory, ideology and subconscious desires" (Passerini 1979, p. 84). They likewise recognized that by using interviews and other oral sources to complement the historical record, they could serve a social purpose. For example, in 1988, oral historian Paul Thompson (2016, pp. 34–35) noted that:

[u]ntil the present century, the focus on history was essentially political: a documentation of the struggle for power, in which the lives of ordinary people, or the workings of the economy or religion, were given little attention except in times of crisis. . . . This was partly because historians, who themselves belonged to the administering and governing classes, thought that this was what mattered most. . . . But even if they had wished to write a different kind of history, it would have been far from easy, for the raw material from which history was written, the documents, had been kept or destroyed by people with the same priorities. The more personal, local, and unofficial a document, the less likely it was to survive. The very power structure worked as a great recording machine shaping the past in its own image.

For this reason, the life history interview – and the practice of oral history more generally – was conceptualized by many early practitioners as a powerful means of challenging the elite power structures that had previously controlled the production of history in many settings around the world. Thompson focuses on documenting the life histories of working class people to enhance understanding of working class families and communities. However, early efforts to address this power imbalance are not limited to working class communities. Oral historian Daniel Kerr (2016) has highlighted the pioneering work of popular educators like Myles Horton, Septima Clark, Ella Baker, and Paolo Freire, who starting in the 1930s were actively conducting research among oppressed communities in the United States. Their common goal was to evoke the life experiences of the working classes, people of color, and members of lesbian, gay, bisexual, transgender, and intersex (LGBTI) communities, among other people they perceived as vulnerable to political violence. They then disseminated the resulting narratives to the public to promote enhanced understanding of the structural oppression and discrimination that undermined the social vitality of these marginalized communities. Taken together, the "radical" social roots of the life history interview – at least in terms of their application across the Global North – become clear, as does the rationale underlying practitioners' focus on the life history interview as a means of "democratizing history," revealing the multiple truths of people's lived experiences and complicating the grand historical narratives that might otherwise exclude them from the historical record, giving rise to a popular "history from below" (see, e.g., Samuel 1976).

However, in deciding whether the life history interview might be an appropriate method for a given research project, it is important to assess the project's legal and ethical merits and whether it is personally, culturally, and politically appropriate for participants. As a starting point, researchers should familiarize themselves with their discipline's best practices surrounding "informed consent," according to which the researcher provides potential recruits with enough information up-front to ensure that they clearly understand "the facts, implications, and future consequences" of their participation in the research project, enabling them to make an informed decision as to whether or not they want to participate (OHS 2012). In instances where the desired participants are below the age of consent or have impaired judgement – for example, due to severe learning disabilities, dementia, or intoxication – it may be impossible for them to give informed consent, requiring special protocols to be introduced, such as the acquisition of informed consent from a legal guardian.

Additionally, due to the method's goal of evoking detailed life stories – often documented over multiple interview sessions stretched over days, weeks, or even months – participants often become highly visible within the research project, posing potential challenges to the researcher's ability to preserve participants' confidentiality, where requested (OHS 2012). Researchers should consider whether in visiting with participants – particularly when the researcher is a visible outsider in the communities where they conduct fieldwork, or where family, friends, neighbors, and local officials are likely to take an active interest in the comings and goings of newcomers – they will be able to maintain people's confidentiality, if participants request it. Similarly, efforts to anonymize participants' contributions can be easily stymied. The personal details that often emerge during life history interviews can make it possible for participants' friends, families, and other intimates to identify which pseudonym the researcher has used in reference to their contributions to their writing, presentations, and exhibits, even in the absence of photographs and video and audio recordings (Jessee 2011; see also ► Chaps. 106, "Ethics and Research with Indigenous Peoples," ► 107, "Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds," and ► 108, "Ethical Issues in Cultural Research on Human Development").

It is also important to consider up-front the labor we are requesting of our participants in conducting lengthy interviews, particularly if we are not offering to reimburse them for their time. While some people might be eager for an opportunity to speak at length about their lives and not expect or need compensation, others might find that the researcher's requests place them in a difficult position personally or financially, by taking time away from their daily subsistence activities and employment, for example (Liamputtong 2007, 2010). While researchers may have valid ethical concerns about paying participants for their life histories – key among them the fear that the promise of money might coerce people into consenting to participate in research projects against their best interests (see, e.g., Russell et al. 2000; Head 2009) – organizations like the American Anthropological Association warn researchers against exploiting participants and call upon them to "compensate contributors justly for any assistance they provide" (AAA 2012). Furthermore, where researchers deem financial compensation to be inappropriate or infeasible,

there are a host of other options for “giving back” to the participants and communities who feature in our research, from engaging in volunteer work to ensuring we work with participants to identify “research-as-intervention” opportunities that can facilitate meaningful positive change in our participants’ daily lives (Swartz 2011, p. 50).

The researcher’s schedule and budget is another key concern related to the life history interview. Due to the lengthier nature of the life history interview and the large amounts of data it can generate, researchers should carefully consider up-front how many life history interviews they can reasonably complete given the time frame for their research project and the funds available to them. This involves consideration of not only the interviews themselves but costs associated with travel to and from the interviews and potential financial and in-kind compensation for participants and the time involved in transcribing or summarizing, editing, annotating, and analyzing the interviews in preparation for their eventual dissemination in the various formats desired by the researcher and their collaborators. There may also be costs and additional time requirements associated with the different software researchers decide to use in editing and annotating their interviews, or making them available via online repositories and archives, all of which should be assessed prior to the start of interviews and budgeted for accordingly.

3 Conducting Life History Interviews: Best Practices

Once the researcher has addressed these preliminary considerations and decided to proceed with life history interviews, there are a number of reliable resources they can use to familiarize themselves with the “best practices” for conducting and analyzing interviews. Particularly notable, the American Oral History Association (OHA 2009) and Oral History Society (OHS 2012) offer valuable guidelines for conducting interviews that range from the aforementioned legal and ethical concerns to more practical concerns related to drafting the necessary consent and recording agreement forms and creating an appropriate interview guide for your research project. A number of oral history centers around the world also offer introductory workshops and templates that newcomers to the field can use to prepare themselves. For example, in addition to running regular training workshops, the Centre for Oral History and Digital Storytelling at Concordia University in Montréal, Canada, has an impressive online “toolbox” that includes free webinars on the basics of oral history interviewing, transcription, and walking interviews as well as sample consent forms, among other valuable resources (COHDS 2018). Similarly, the Columbia Center for Oral History Research in New York offers workshops and short courses but has also drafted a series of research guides that are freely available on its website, including one that specifically addressed the challenges posed by using oral history methods to document and interpret conflict and related human rights abuses (CCOHR 2018).

However, one of the most accessible and thorough sources of information on best practices surrounding the interview is oral historian Valerie Yow’s *Recording Oral History: A Guide for the Humanities and Social Sciences* (2014). In addition to detailing all aspects of what she terms the “in-depth interview,” Yow includes a

series of appendices that practitioners can use to create their own sample interview guide, which outlines the questions they intend to ask, legal release forms specific to the United States, archive release forms for the long-term preservation of the interviews, participant information sheets for informing potential participants about the researcher's project and their rights within it, indexing forms for annotating the resulting recordings, and citation guidelines. In terms of the practical documentation that researchers should have in hand in preparation for starting the interview phase of their research, *Recording Oral History* is an essential source of information based on Yow's decades of experience working in academic and public settings.

To this end, most guidelines recommend that first-time interviewers gain some kind of training in oral history prior to recruiting potential participants and take the time to ensure that all necessary paperwork and related procedures for establishing informed consent, arranging for long-term preservation of the interviews, and other key elements of their project are in place. In instances where researchers are working in foreign contexts, in conflict-affected settings, or on potentially sensitive subject matter, they may want to pursue additional forms of training, such as Basic First Aid, Hazardous Environment Training, and trauma counseling. They should also make sure they clearly understand their legal and ethical responsibilities as outlined by their host institutions, which likely requires some form of institutional ethics approval, but may also be involving completing a risk assessment form for insurance purposes in the event the researcher plans to work abroad. Researchers should also take care to familiarize themselves with any code of ethics, laws, or research approval processes specific to the communities and nations in which they will be working (Fujii 2012). For example, in order to conduct human subject research in Rwanda at present, foreign researchers are required to arrange various forms of approval including at minimum ethics approval from the Rwanda National Ethics Committee, a research permit from the Ministry of Education, and a research visa from the Rwanda Directorate General of Immigration and Emigration. They may also require institutional approval from other government ministries or community-based organizations in order to secure the necessary supporting paperwork from in-country partners in their research, as all research in Rwanda must be collaborative in order to ensure the knowledge being gained benefits Rwandans, as well as foreign researchers (Jessee 2012).

Most guidelines similarly recommend that researchers prepare an interview guide that details the specific questions and themes they intend to address. The interview guide is typically understood as a backup, rather than a strict guide to which the interviewer and interviewee must adhere. To this end, the life history interview may be quite different from other types of interviews. Generally speaking, the life history interview should be directed by the interviewee, with the interviewee speaking in as little or as much detail as they feel is necessary to narrate those events and experiences they feel are most relevant. However, interviewers may still find it helpful to prepare an interview guide to get them thinking in advance about the kinds of topics they want to discuss. And in the event that the interviewee is reluctant to take the lead in the interview, the guide can be a helpful point of reference for kick-starting the conversation until the interviewee feels more comfortable.

In drafting a life history interview guide, many practitioners advocate a chronological approach. For example, Yow's sample interview guide begins with prompting the interviewee for some basic background information related to their birthplace, parents' names and occupations, and family's cultural life before shifting to specific memories related to the different life stages – the interviewee's childhood, adolescence, and key life events, such as marriage and raising children – until the interviewee reaches the present (Yow 2014). This makes for a logical narrative format in many Euro-American settings, though it is important to be mindful that in some communities, "good storytelling" may look quite different (Cruikshank 1990; Krog, Mpolweni, and Ratele 2009). Furthermore, adopting a chronological approach may prompt interviewees to revisit their memories in a way that is distressing or culturally inappropriate. Oral historian Amy Tooth Murphy (2014) has noted that in her life history interviews with British lesbians, her efforts to encourage a chronological format in the interviews often forced the women she interviewed to revisit painful and distressing memories that they might otherwise have chosen to avoid or reflect upon at a different point in the interview.

I encountered a similar phenomenon in my fieldwork in post-genocide Rwanda and Bosnia-Herzegovina. While interviewing people whose lives had been negatively affected by genocidal violence, I noticed that participants often seemed to find it jarring and painful to start with their childhood, reflecting on memories of deceased loved ones and a way of life that no longer existed, even in cases where they demonstrated remarkable resilience in their post-genocide lives. Thus, I quickly adapted my life history interview guide to start with an open-ended request: "Tell me about your life." Participants may still have chosen to talk about distressing memories or experiences – indeed, people's personal experiences of genocide were typically focal points of the interviews I conducted – but at least participants were able to broach these memories on their own terms and in their own time (Jessee 2017b, pp. 83–84). Furthermore, encouraging participants to take the lead in the interview granted me a sense of which experiences they found possible to narrate. Simultaneously, it afforded me a sense of which topics participants might find incommunicable, unbearable, or irretrievable, and where I might need to proceed with special caution or sensitivity, or avoid altogether (Greenspan 2014). In settings where people are negotiating trauma, defined as a range of psychological or psychosomatic symptoms that temporarily interfere with the "normal functioning" of their mind or nervous system (Rothschild 2011, p. 18), or post-traumatic stress disorder, described as long-term "clinically significant distress or impairment of an individual's social interactions, capacity to work or other important areas of functioning" resulting from "exposure to actual or threatened death, serious injury or sexual violation" (American Psychiatric Association 2013), this approach can provide participants with a crucial degree of control over the interview. This, in turn, can make for a more positive and less distressing experience than might otherwise be the case if the researcher insists upon the more common chronological format or otherwise attempts to adhere to a strict interview guide or questionnaire.

To this end, the life history interview can be a more intimate form of interview than participants typically expect in settings where shorter, thematic interviews

aimed at understanding a clearly defined phenomenon are the norm. Where time permits, non-recorded pre-visits with potential participants – perhaps combined with open discussion of the project and its intended outcomes as guided by the participant information sheet – can be valuable for helping to establish positive rapport between the interviewer and the interviewee. It provides the interviewee with an opportunity to ask questions and address any concerns they may have about the project or the researcher. The OHA’s “principles and best practices” guidelines (2012) note that the interviewee should have a clear understanding of their rights surrounding the interview, how the interview will be used within the broader project including copyright agreements, access restrictions, and expected forms of dissemination, and whether or not they would like their confidentiality to be maintained in the documentation, preservation, and dissemination of any data that results from their participation. Given the pre-visit typically occurs off-the-record, it can be a good time to map any topics that participants are keen to discuss and conversely any subjects that they consider off-limits for the interview. The pre-visit is also an ideal time to address any potential harms that could affect participants as a result of the specific subject matter being discussed. For example, if it is possible that the interviewee might – in the course of reflecting on their life – discuss past or present crimes or other potentially sensitive subjects that places the researcher in a legally or ethically problematic position wherein they may feel obligated to inform the police, the researcher should mention this potential risk and take steps in conversation with the interviewee to ensure this risk is minimized, as much as is possible. In my work with convicted perpetrators of the 1994 genocide in Rwanda, I always informed the people I interviewed up-front that it may not always be within my power – due to the likelihood of surveillance within the prisons – for me to guarantee them confidentiality, and so to be especially careful of discussing crimes for which they had not already been convicted. This was a primary reason why so many of the convicted perpetrators I interviewed spoke about atrocities they “observed” within their communities, often without indicating their role in these atrocities or who else might have been involved (Jessee 2017b, pp. 149–188).

The necessity of such caution is demonstrated by the recent controversy surrounding Boston College’s “Belfast Project,” which used oral history methods to document “The Troubles” in Northern Ireland. The project’s participants included former leader of the Irish Republican Army (IRA), Brendan Hughes. As part of his interviews, Hughes allegedly discussed his role in organizing the Bloody Friday attack, during which the IRA detonated approximately 19 car bombs across Belfast in an hour on 21 July 1972, killing 9 and injuring an estimated 130 civilians (BBC News 2017). He also allegedly disclosed information about the criminal actions of Sinn Féin’s leader, Gerry Adams, who had controlled a paramilitary squad that was allegedly responsible for kidnapping, murdering, and disappearing perceived enemies of the IRA. Knowledge of these disclosures prompted the Police Service of Northern Ireland to submit a legal bid in 2011 to gain access to all of the Belfast Project interviews. The project’s lead researcher, Anthony McIntyre, received a subpoena demanding he give the police the relevant interviews, and upon refusing found himself embroiled in a legal battle (McDonald 2016). This, in turn, prompted

panic throughout the oral history community related to whether practitioners can, in such extreme circumstances, genuinely protect participants from legal investigation and prosecution where police suspected that participants have discussed their own or others' criminal actions. The OHS issued a formal statement in 2014 that condemned the Police Service's efforts to violate participants' confidentiality within the Belfast Project but simultaneously noted that the case should serve "as a warning not only to oral historians, but to all those engaged in collecting historical data about criminal activity or allegations of criminal offences" (OHS 2014). This warning is particularly well-considered by those engaging in life history interviews, again due to the detailed information and lengthy narratives we often elicit from participants, which can make it easier for people to be identified even in the absence of a name, date of birth, or other information.

As the life history interview takes shape, practitioners encourage participants to take whatever time is necessary to fully develop their life story. Ideally, the researcher should not need to ask many questions, but merely follow the interviewee's lead. Where the interviewee requests that the researcher ask questions to help guide them through the interview, these questions should be open-ended to encourage reflection, rather than "yes" or "no" responses from the interviewee (Yow 2014, p. 79; Ritchie 2015, p. 92). Likewise, the interviewer can use follow-up questions and prompts to direct the interviewee and demonstrate interest. However, in the life history interview, these kinds of interruptions should, ideally, be minimized to empower the interviewee and avoid skewing the narrative with the researcher's opinions (Ritchie 2015).

The life history interview may need to be conducted over several sessions in the event that the interviewee has a great deal to say, or just as likely, may be brief or perfunctory in the event that participants feel they do not have much of importance to say on-the-record, for example. Practitioners generally regarded it as polite to set an approximate time limit in advance, to which they then try to adhere to avoid exhausting themselves and the interviewee (OHA 2009). Likewise, the resulting narrative may be a carefully rehearsed version of events, a spontaneous reaction in the moment to the interviewer and their interests, or a blend of both. Oral historian Lynn Abrams (2016, pp. 64–86) has written extensively about the important interplay between the subjectivity – an individual's sense of self – of the interviewer and interviewee, and how this may influence any interview's course and content, among other interactions between researchers and participants. She encourages practitioners to be especially mindful and honest about the way that gender, heritage, age, class, profession, and other intersecting facets of the researcher's and interviewee's identities may influence the interview (see also, Bouka 2015). Sociologist Kathleen Blee's work (1993, 2002) among women members of the Ku Klux Klan is particularly helpful for those researchers who work among so-called "unloved" participants – "individuals who are immersed in events or subject matter marked by conflict and controversy, and from whom other often seek to distances themselves due to the morally reprehensible nature of their actions" (Jessee 2017b, p. 152; see also, Fielding 1990). While ideally researchers hope to establish positive rapport with participants and conduct insightful interviews marked by "engaged and sympathetic interaction," Blee (1993, p. 327) recognizes this may not always be possible or desirable.

To this end, practitioners like oral historian Alexander Freund (2013) advocate paying particular attention to not just the words spoken in an interview but the silences that become apparent. It can be difficult for interviewers to know where to draw line between probing silences to determine why they might exist – a case of genuine forgetfulness on the part of the interviewee, for example, that is not indicative of a conscious plan to withhold what might otherwise be important information for the researcher – versus respecting the participant’s privacy, where discussion might cause them emotional distress or embarrassment, for example. Freund (2013) has called upon researchers to develop an “ethics of silence” that recognizes a participant’s silence as an act of agency that should be prioritized above the researcher’s desire to document “the whole story” or to amplify the experiences of people who might otherwise have been excluded or underrepresented in the historical record. Indeed, Freund reminds us that silence – particularly when manifested in secrets, taboos, and misinformation – can be a powerful weapon for subaltern communities. For this reason, he recommends taking the time to document silences in the interview in the transcripts and summaries we produce to make them visible in the historical record. He likewise encourages practitioners to ask questions about silences – ideally during an unrecorded session after the interview, where possible – to get “the story behind the story.” This does not mean forcing participants to answer questions on topics they have clearly expressed a desire to avoid, but rather asking them why they wish to avoid the topic, rather than the researcher making assumptions as to their motives and potentially colonizing the silence with their interpretation (see also, White 2000).

Once the interviewee concludes their life history, the researcher may want to ask some follow-up questions in order to address any lingering research interests that went undiscussed or to otherwise achieve some balance between the project’s broader objectives and the interviewee’s narrative (OHA 2009). Oral historian Donald Ritchie (2015, p. 108) advocates having a prepared “wrap-up question” that encourages the interviewee to reflect back on their life as a whole. It can also be helpful to debrief with the interviewee, where time permits, to invite them to reflect on the interview experience itself. Before finally ending the session, the researcher should briefly revisit the consent and recording agreement forms to make sure that the interviewee is comfortable with the conditions that surrounded their interview and that any changes to the interviewee’s wishes are clearly documented (OHS 2012). The final versions of these forms should be archived alongside any data that results from the life history interview.

4 After the Interview: Analyzing and Disseminating Life History Interviews

This leads to considerations of how best to proceed after the life history interview. Where participants have requested confidentiality, researchers should immediately ensure that all personally identifying information has been edited out of any interview recordings and related materials that will end up in an archive. This includes

any transcripts or time-coded summaries they might produce. It may also be desirable, where time, funding, and participant interest permits, to vet these documents with individual interviewees to ensure they are happy with the final content of the interview and satisfied that their confidentiality is being maintained. This is particularly good practice in settings where the political climate surrounding the topics discussed in the life history interview can change rapidly and unexpectedly, as is often the case in conflict-affected communities or when dealing with politically controversial subject matter.

As researchers begin to analyze the life history interviews they have conducted, in addition to the aforementioned importance of silences, they should be aware of the potential for what anthropologist Antonius Robben (1996) has termed “ethnographic seduction.” Robben (1996, p. 74) defines ethnographic seduction as “a complex dynamic of conscious moves and unconscious defenses” through which an interviewee attempts to “influence the understanding and research results of their interviewers.” He argues that ethnographic seduction is a common element of any human subject research that can significantly impact both the content and course of an interview or ethnographic encounter, as well as how researchers analyze the resulting data. This risk may be heightened surrounding the life history interview, the intimate and prolonged nature of which may foster deeper emotional connections between the interviewer and interviewee. For this reason, Robben cautions researchers to be especially mindful of “frequent thoughts about the interviewee, possibly accompanied by depression, dreams and fantasies, as well as slips of the tongue and the compulsion to talk to others about the interviewee” as signs that ethnographic seduction could be interfering with the researcher’s ability to analyze and understand participants’ narratives in a balanced and critical manner (Robben 1996, p. 99; see also Jessee 2017a, p. 338).

I constantly navigated this phenomenon in my work among convicted perpetrators of the 1994 genocide in Rwanda, many of whom insisted they were victims, even as they discussed the ways they contributed to the torture, murder, and mutilation of their ethnic Tutsi compatriots. At times, their claims to victim status seemed genuine as they described, for example, being coerced by armed militia who threatened to kill them if they did not agree to join in the massacre of Tutsi civilians in their communities. But in other instances, their claims seemed disingenuous – cloaked in a morally reprehensible understanding of the past and the sense that the atrocities they perpetrated were somehow justified by their nation’s history or perceived historical injustices visited upon the Hutu majority by the Tutsi-dominated monarchy that had ruled the nation prior to independence in 1962 (Jessee 2018). As such, I had to be keenly aware of how my efforts to build positive relationships with convicted perpetrators might influence my understanding of the genocide and Rwandan history and by extension, my research outcomes – at times, it seemed more so than other interviewees and informants. However, Blee (2017, p. 16) has noted that any relationships that emerge in the course of fieldwork – from gatekeepers who provide permits and contacts to the specific individuals who are ultimately interviewed – will shape a researcher’s theorizing “by affecting not only what researchers can access but what they notice or find puzzling and what they regard as significant in a research setting.”

To this end, the process of analyzing life history interviews can be a lengthy endeavor and one that involves multiple listenings to the recordings and revisiting associated data in order to glean a thorough understanding of not only what the interviewee has said but the deeper meaning behind their words. As indicated in the introduction, the ideal outcome is for the researcher to develop a nuanced understanding of the meaning the past has for individuals in the present, as informed by their lived experiences and the broader cultural circuit in which they are embedded, as well as the myths they rely upon to give meaning to their lives. This is typically accomplished through a combination of reconstructive analysis, whereby the life history is used to reconstruct an approximation of a participant's lived experiences, and narrative analysis, which "identifies and then explains the ways in which people create and use stories to interpret the world" to create a "storied past" (Abrams 2016, p. 106). As part of this, practitioners may choose to analyze a single life history in conversation with a broader body of literature around particular events or kind of experience, for example. However, a more common approach is to bring multiple life histories into conversation by using excerpts that offer "thick description" on the topics being explored with the goal of identifying commonalities and outliers on a wide range of phenomenon from physical and mental health challenges in the aftermath of trauma to reconstructing working class lives in different settings around the world (Geertz 1973).

In terms of dissemination, these days the sky is the limit. Typical academic outcomes include theses and dissertations, as well as academic articles and books aimed at a specialist audience. But the life history interview is increasingly acknowledged as an integral way of demonstrating how policies, ideas, and events take on different meanings over time in response to a wide range of personal, social, political, and historical factors. In the process, life history interviews can amplify the voices of people whose perspectives are typically absent or obscured in the historical record in many contexts. For these reasons practitioners are increasingly experimenting with ways of making these interviews publicly accessible to ensure they have impact beyond academia. Across the physical and social sciences, and arts and humanities, researchers are using digital media to make the life histories they document and analyze accessible to the public in different ways – from museum exhibits and educational documentaries to video games and graphic novels. The rapidly expanding field of digital storytelling is particularly provocative and has captured the interests of publics around the world, as evidenced by the range of online workshops and related educational materials aimed at teaching people to engage in digital storytelling activities in their communities, as well as the vast number of digital storytelling projects and organizations that have taken shape around the world in the last 25 years (Lambert 2013; see also ► 74, "Digital Storytelling Method").

Digital storytelling is not without its critics, however. Freund (2015), among others, has warned against digital storytelling of the kind championed by organizations like the US-based multinational and transcultural phenomenon, StoryCorps. Freund (2015, p. 96) argues that StoryCorps "frequently aligns itself with (or appropriates) oral history, reinforces neoliberal values of competitive individualism

and thus depoliticizes public discourse” in its efforts to bring people together around what appear to be positive, healing, and empowering narratives of personal transformation and social change. The Smithsonian’s National Air and Space Museum’s senior curator, Roger Launius (2013, p. 31), shares Freund’s criticism, noting that the homogenizing story of America as “one nation, one people” promotes nostalgia for a mythical past in which the American people were “all one.” Freund (2015, pp. 108–109) argues that the resulting “consensus history” is often invoked with particularly dangerous consequences by the political and social right, who use it to “silence citizen critique” of the state by situating hardship and failure as a matter of individual responsibility. For this reason, he advocates that practitioners resist the “vortex of storytelling” by ensuring that they adequately historicize the life history interviews and related materials that they analyze, and in dissemination take care “not to be mesmerized by the emotional power of the storytelling phenomenon or by the economic success of the storytelling industry” (Freund 2015, p. 130, 131). Such warnings are particularly salient in conflict-affected communities and other highly politicized settings where the international community, state-level actors, and other parties may have a stake in encouraging people to adopt and adhere to an idealized “single story” that might not accurately represent ordinary people’s lived experiences or might serve to silence those people whose experiences contradict the desired single story (Adichie 2009).

5 Conclusion and Future Directions

Taken together, this chapter has offered readers a starting point for thinking through the benefits and challenges that surround the life history interview as a methodology. It has demonstrated the democratizing potential of the life history interview as a means of engaging with people’s intimate life experiences and the meaning they attribute to their past as a result of the cultural circuit in which they are embedded and bringing this highly personal interpretation into conversation with the typically elite-dominated historical record. But it has also explored the potential limitations of the life history interview, particularly in contexts where government surveillance makes it difficult to ensure participants’ confidentiality and safety, as well as the well-being of others involved in the research project. Finally, it has pointed readers to key readings on the current “best practices” that life history interviewers typically adhere to in their research and offered a preliminary overview of key debates regarding the analysis and dissemination of the resulting life histories. The overall goal is to promote a high ethical standard in the elicitation and dissemination of life history interviews, regardless of the audience for which they are intended.

Despite the range of literature and related guidance on the use of life history interviews, the method is changing rapidly and engaging an ever-widening range of individuals and communities around the world. While practitioners have been excellent to date at articulating the ethical and legal responsibilities to which they should adhere, and analyzing the intersubjective nature of the life history interview and the way that individual and collective memories can shape life histories in

different contexts, it is crucial that practitioners continue to reflect on the method's "best practices" and speak about the ways – both overt and subtle – that they adapt these practices in their research. This is particularly true of practitioners who come from diverse backgrounds, whose experiences of conducting life history interviews as people of color, members of religious minority communities, and gender or sexual minorities, for example, may be substantially different from those of the cisgender, heterosexual, Judeo-Christian, white majority in the Global North that typically dominates the literature (Berger Gluck and Patai 1991; Bouka 2015; Fobear 2016). It is similarly important for researchers who are working across national, regional, and linguistic boundaries or in crisis- or conflict-affected communities to discuss the particular challenges and ethical and legal responsibilities that they negotiate in using life history interviews to evoke people's experiences and opinions. And finally, as we increasingly experiment with digital media as a means of disseminating the life histories and related information that we evoke, honest reckonings with the benefits and limitations of the various technologies that are available could only help improve our understanding of which options might be personally, culturally, and politically appropriate in different contexts.

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Ethnographic Method

26

Bonnie Pang

Contents

1	Introduction	444
2	Reflexivity	446
3	Traditional Forms of Ethnographic Methods	447
3.1	Fieldwork	447
3.2	Participant Observation	448
4	Innovative Forms of Ethnographic Methods	449
4.1	Visual Methods	449
4.2	Sensory Methods	451
5	Opportunities and Perils of Using Ethnographic Methods	452
6	Conclusion and Future Directions	453
	References	454

Abstract

This chapter explores the use of a range of ethnographic methods within qualitative methodology. Alongside introducing the building blocks of ethnographic methods, with a focus on reflexivity, participant-observation, fieldwork, and visual and sensory methods, it will draw upon my experiences in studying young Chinese Australians' lived experiences in health and physical activity. My experiences in the field provide insights into the potentials and perils of using some of these ethnographic methods and issues navigating research ethics. I emphasize the advantages of an approach that allows for innovative and unique interactions between the researcher and research participants within the

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443

participants' real-life environments. The use of innovative ethnographic methods encourages thinking and practice beyond traditional modes of enquiry and beyond understanding the participants' lived experiences through texts and numbers alone.

Keywords

Ethnographic methods · Participant-observations · Reflexivity · Visual methods · Sensory methods · Lived experiences

1 Introduction

Ethnographic methods fall within the broader category of qualitative methodologies and are commonly used within health-related research (Berg 2004; Liamputtong 2013; Willis and Anderson 2017). It entails a variety of research techniques that aim to understand human actions, thoughts, and behaviors. Ethnographic methods can be used to gain further understanding of the research issues lurking behind the scenes of surveys and quantitative methods. They are well suited for understanding local points of view. Local voices – in particular, those of minority backgrounds, who may be linguistically diverse and disadvantaged, and whose voices have been undermined in research – are relatively difficult to access through traditional survey methods (e.g., Pang et al. 2015; see also ► Chap. 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology”). This chapter introduces the main concerns in using various ethnographic methods (with a focus on reflexivity, fieldwork, observations, visual methods, and sensory methods). I also examine the potentials and perils of doing reflexive, embodied, and emplaced research in the field, offering a combination of hands-on examples and my own research experiences on how to carry out these methods effectively. Drawing upon examples from my ethnographic research with young Chinese Australians in health and physical activity, I examine some of the distinctive characteristics of fieldwork and interactions with participants in the environment. In doing so, I argue that the success of conducting ethnographic research methods require a relational, flexible, and reflexive informed approach. I also put forward the need to conduct sensory ethnographic research that gives more consideration to the multiple senses and embodied dimensions in an in-depth understanding of people's lived experiences. The chapter ends by highlighting future directions for ethnographic research methods in qualitative health and physical activity research.

Individual methods that are commonly used within an ethnographic research study include participant observation, interviews, and surveys. More contemporary forms of ethnographic methods include visual, digital, sensory, and spatial approaches. These forms of ethnographic methods can be very valuable in gaining a deeper understanding of a particular social group or a specific problem. The use of a range of traditional ethnographic methods is well covered in existing research methodology books (e.g., Liamputtong 2013, 2017). Recent ethnographic research frequently involves the use of

digital, visual, and audio technologies in the practice of such methods (see Pink 2007, 2015). Other less conventional methods may entail, for example, arts-based methods and collaborations between the researcher and the researched by producing a video, writing a song, or inviting the participants to reflexively engage in an everyday or designed activity (Liamputtong and Rumbold 2008; see chapters in the ► Chap. 61, “Innovative Research Methods in Health Social Sciences: An Introduction” section of the handbook).

In using various ethnographic methods, there is a need to follow a set of practices that explores social life as the result of an interaction of structure and agency in people’s everyday practice and experiences. Several factors may compromise the trustworthiness of the research data collected from participants, including participants’ fear of giving “incorrect” answers, power imbalances, and a lack of rapport and trust between the researcher and researched (O’Reilly 2012). Social researchers often enter one of the three different forms of power relations in their ethnographic work (Tuck and McKenzie 2015). Reciprocal relationships are those in which the researcher and participants are in similar social positions and have relatively equal benefits and costs in participating in the research. Asymmetrical relationships are those in which there are significant differences in the social positions of the researcher and participants; the researcher may have relatively better access to cultural and economic resources and/or be in a position of greater power than the participants. Power exists in all social interactions, and social research cannot be excluded. In responding to potentially exploitative relationships, Dowling (2015) proposes two strategies that researchers can draw on to minimize power imbalances. First, researchers can involve participants in the design and conduct of the research, for example, by asking participants to set the research questions that need to be examined. Researchers can also invite participants to verify or “talk back” to the researchers’ interpretations throughout the research process.

Since ethnographic research takes place in the real world with human beings, there are a number of ethical concerns to be aware of before, during, and after the study. For example, researchers must convey clearly to the participants the rationale of the research, develop ongoing rapport throughout the research process, and have an ethical exit strategy (Morrison et al. 2012, p. 200). McCorkel and Myers (2003) comment that “the assumptions, motivations, narratives, and the relations which are part of the researcher’s backstage” are often invisible in the practice of qualitative research. Information about the situatedness of the knower, the context of discovery of the knowledge, and the relation of the knower to the subjects of the study are important in the production of legitimate knowledge (McCorkel and Myers 2003). Authenticity and fairness are regarded as a unique and core characteristic of interpretivist research (Schwandt 2000). The main concern of ethnographic research as a form of interpretivist research is to show the diverse “realities” of the participants’ voices. Researchers need to “be there” and represent fully their participants’ lives in relation to the research questions. This is what Jackson (1995, p. 163) suggests as “the authenticity of ethnographic knowledge depends on the ethnographer recounting in detail the events and encounters that are the grounds on which the very possibility of this knowledge rests.”

2 Reflexivity

The use of reflexivity in ethnographic research serves to ensure researchers have systematically and rigorously conducted their methodology and their self as an instrument of data collection and representation. This is because ethnographic researchers are part of the social world in which they study, which in turn raises concerns over issues of subjectivity when attempting to demonstrate the trustworthiness of their research findings. Finlay and Gough (2003) describe reflexivity as a process which researchers conduct thoughtful, self-aware analysis of the inter-subjective dynamics between researcher and the researched. Researchers are required to be aware of ongoing dynamics and power relations in the research process and to reflexively draw on appropriate ethnographic methods to apply in the research with the participants. There are some possible questions to reflect on throughout the research process and to modify the process where appropriate (Dowling 2015):

- Would you be doing anything differently based on the participants' response to your methods?
- Could you justify your actions to others?
- Are you presenting what you heard and saw or what you expected to hear and see?
- Are you reproducing stereotypical representations?

Given that these concerns are often undermined and ignored in qualitative research, it is important to highlight some of them when conducting various ethnographic methods backstage. Below is an example of how I conducted reflexivity in my research (Pang 2016):

I have conducted an ethnographic research study with 12 young Chinese Australians aged 11–15 and their Health and Physical Education teachers in two Brisbane schools. The research was based on fieldwork and observations, in-depth interviews, and drawing-elicitation methods, and it provided rich data on the students' lived experiences in their physical activity lives. Research argues that the essentialist notion of being a complete insider or outsider as a researcher is problematic (Fletcher 2014). Some of the central questions about the insider/outsider debate in researching with participants, especially with those who are different to us include, e.g., who can be a "knower" (Sparkes 2002), and what are the relationships between "self and other" and the "self-as-other" (Fletcher 2014). In response to this debate of insider and outsider in the research process, I concluded that my phenotype, interests, age, class, gender, and country of origin all shaped the questions that I posed to the participants, my interactions with the participants, and the focus of my observations in schools. It seems that a similar racial identity to the young Chinese students' may add a dimension of diversity and depth to the data collected (e.g., in discussing my English accent and linguistic capacity as well as issues of racism and microaggressions) and rapport built in this research process (e.g., in discussing my different lifestyles in Australia and Hong Kong and my career choices as a Chinese person) that might not have surfaced if this research had been conducted by White researchers born in Australia. The rich and/or different data are a result of how the Chinese students perceived me as a "Chinese young academic," "family member," and/or "Chinese with good English," and how I interacted with the students during the fieldwork.

This reflexivity process is important to overcome what is usually referred to as the researchers' bias in the positivistic paradigm (Davies 2008). When researchers conduct ethnographic methods, reflexivity allows them to acknowledge human subjectivity in the research process. The participants are indeed a constructivist outcome of the intersubjectivity between the researcher and the researched (Finlay and Gough 2003).

3 Traditional Forms of Ethnographic Methods

Traditional approaches to ethnographic research endeavor to collect information from the field through interviews, fieldwork, and observations. These traditional forms of ethnographic methods aim to unravel the contextual meanings of the everyday practices in their participants' natural settings. The focus of such methods is to obtain a comprehensive understanding of a specific problem or question. Fieldwork and observations are discussed in detail in the following sections.

3.1 Fieldwork

Fieldwork is an essential attribute of ethnographic methods. O'reilly (2012) defines fieldwork as a form of inquiry that requires a researcher to be immersed personally in the ongoing activities of participants in the research. Fieldwork requires the researcher, being the main instrument of data collection, to have a clear intent apart from merely a presence in the field (O'reilly 2012).

In recording field notes, the researcher records not only his or her notes on the community or context but also his or her feelings and emotions regarding the field experiences. Goffman (1989, p. 125) notes that field research involves "subjecting yourself, your own body and your own personality, and your own social situation, to the set of contingencies that play upon a set of individuals, so that you can physically and ecologically penetrate their circle of response to their social situation, or their work situation, or their ethnic situation." These personal experiences should be analyzed in the ongoing fieldwork process with respect to the context and researchers themselves, as well as the insider and outsider perspectives, or the space between being an insider and outsider (Dwyer and Buckle 2009).

In the process of conducting fieldwork, we therefore need to be cautious of the significance of understanding ongoing meanings and how researchers interpret them. Ontologically, human beings are the primary focus of the study, and they construct multiple realities that are complex, multifaceted, differently expressed in specific contexts, and continually undergoing changes and transformations. Epistemologically, in order to gain an understanding of such realities, the aim of conducting ethnographic methods is not to begin with predetermined hypotheses to be proved or disproved as objective fact, but with open-ended exploratory questions to learn as much as possible about those realities. This process enables the researcher to describe these etic realities (the perspective of an outsider looking in) and the connections between them and the emic view (the insider perspective) of participants (Guba and Lincoln 1994; see also ► Chap. 6, "Ontology and Epistemology").

3.2 Participant Observation

Participants might respond to interviews with what they should do (the norm), and thus, observation provides a complementary means to reveal the enacting culture through their “patterns of behaviour” (Bernard 2017). Accurate observations are fostered by systematic and scrupulous attention to detail. Observation is immersing oneself into the actual world of culture in study. This suggests that the ethnographic method is connected to naturalism, in which the social world is studied as far as possible in its natural state (Atkinson and Hammersley 2007). Observations also provide first-hand encounters with the research interests (Merriam and Tisdell 2015) and allow researchers to discover complex interactions in natural social settings (Marshall and Rossman 2014). Bernard (2017) suggests that the focus of observations should include a clear outline in the research design of the boundaries and participants for, and the arrangements of, observations. The ethnographic fieldwork continuum ranges from direct nonparticipant observation to participant observation. An outline of a range of research roles in observations is provided below (Bernard 2017):

- Complete observer (e.g., a researcher with no physical involvement in a sport by remotely observing the sport)
- Observer-as-participant (e.g., a researcher being a newcomer to bodybuilding by being part of the group)
- Participant-as-observer (e.g., a researcher who is familiar with bodybuilding but seeks to understand this sport in a new light)
- Complete participation (e.g., a researcher living in a new city to understand a particular group of people’s health experiences)

There are different stages of participant observation, including the choice of site, accessing the site, navigating field relations, recording data on site, and analysis of observation data (Atkinson and Hammersley 2007). In choosing a site for participant observation, one might choose to focus on a familiar setting and attempt to shed new light on the experience central to the research focus. In the case of unfamiliar sites, researchers should have a good understanding of the chosen community before entering the site for research purposes (DeWalt and DeWalt 2011). Doing fieldwork in a familiar place can be as challenging as it is in an unfamiliar one. The point is, therefore, to strive for balance in choosing a research site that enables the researcher to be both an insider and an outsider (DeWalt and DeWalt 2011).

After identifying an appropriate site, a crucial issue in gaining access to the site is to identify the gatekeepers in order to recruit targeted participants in the site. The difficulty of this process depends on whether the site is a private or public place and how sensitive is for researchers to conduct research on the topic at their site (DeWalt and DeWalt 2011). Generally, gaining access is more challenging when the place is more private, the researcher is not already an insider on the site, and the topic under examination is sensitive. In navigating the field, researchers take their bodies with them on the site. That is, we are embodied subjects, and what we wear and how we conduct ourselves can be a key marker of who we are and how we are perceived

by the participants on the site (Atkinson et al. 2001). Here is an example of how I conducted my observations and field notes during my research:

On the spot field notes, including sketched drawings and jotted notes, were recorded by hand during the day and transferred to the computer afterwards. More recently, I have used iPads/iPhones to jot notes in the field and import them to the computer folders. Field notes included three parts: The first part was an accurate and detailed description of participants' behaviors and appearance (e.g., what the participants were doing) and the physical state of the environment (e.g., what was the place like?). In contrast, the second part included my personal observations and emotional feeling about the event. Sometimes, photos of the place were included to remind me how the place looks and how I feel about the place. And the third part included snippets of thoughts that were linked to the theoretical concepts.

Analyzing the results of observation data will be different depending on the research purpose. For example, observations that involve counting require a structured research design. This may include the presentation of descriptive statistics and how they relate to the context of the research question. When observation is related to understanding the context, analysis will focus on the text and descriptions about the place and people. This will include finding the meaning of the data and drawing on software such as NVivo to organize and interpret the data (Bryman 2016).

4 Innovative Forms of Ethnographic Methods

It is not uncommon to find research projects that only draw on interviews as their main source of ethnographic knowledge. However, these more conventional qualitative interviewing methods have been argued by researchers to inadequately represent the lived experiences of participants in their specific contexts (e.g., Rapley 2004). Indeed, as Pink (2015) notes, the relationship between what *is* said in interviews and knowledge that is not articulated in this way means that there is a need for other methods to reveal further information from participants. Visual methods and sensory methods are discussed in detail in the following sections.

4.1 Visual Methods

The “visual-turn” (Rose 2016) has brought an increasing growth of image-based research in the health, education, and social science disciplines. We are living in a world where “ocularcentrism” (an increasing saturation of images) has a powerful impact on how we experience our lives (Rose 2016). Visualization is a way of interpreting, and thus, interpretation can influence our ways of seeing (Bustle 2003). In using visual methods, researchers are able to represent knowledge in different ways. For example, visual methods can be used to analyze cultural representations on social media so that alternative narratives can be understood. Images have the potential to stimulate reflections that words alone cannot (Schwartz 1989; see also ► Chap. 61, “Innovative Research Methods in Health Social Sciences: An Introduction”). Various visual methods relevant to this discussion include visual ethnography (Pink 2007),

visual narrative (Carrington et al. 2007), visual sociology, image-based research, and photo elicitation (Harper 2002; Clark-Ibáñez 2007), among others (see also ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method”).

Pink (2007, p. 40) highlights that there are three different approaches in using visual methods: “(a) examining pre-existing visual representations, (b) making visual representations, and (c) collaboration with social actors in the production of visual representations.” Visual approaches allow us to ask questions about health and physical activity research such as: *What is being seen/not seen by the participants and how is it socially and culturally shaped? How are we made to see/not see? How are we allowed to see/not see?* Visual methods allow researchers to probe participants’ lived experiences and act as a medium through which emotions and sensitive topics can be expressed more clearly than using linguistic communication alone (Rich and O’Connell 2012).

Harrison (2002) distinguishes between the visual as resource and the visual as topic. The visual as resource means that the use of visual forms is used to explore a particular research question (e.g., the use of drawings to examine how people construct meanings around physical activity). This may also include the use of visual methods to collect data from participants (e.g., the researcher co-producing sketch-mapping with the participant to understand how the participant’s environment has an impact on his or her physical activity participation, as in Azzarito 2010). In other studies, researcher-produced photographs can be used alongside participant interviews (e.g., Hill and Azzarito 2012). These methods, as resources, allow the researcher to enter the participants’ world visually and move beyond the traditional hierarchical relationships between the researcher and researched in positivist research methods (Harrison 2002). The use of visual methods as topic suggests the use of visual forms as the subject of analysis (e.g., analyzing the media representations of young people in body size in online media, as in Millington and Wilson 2012). Below, I expand on photo-elicitation (visual methods as resource), and its use alongside interviews and demonstrate its potential and perils in ethnographic research.

Photo-elicitation is a form of visual method that allows participants’ experiences and meanings related to the research topic to be shared simultaneously and discussed during traditional interviews. Photo elicitation can be used during interviews, which allows participants to discuss dimensions of their social world that may be ignored or taken for granted (Clark-Ibáñez 2007). Photo-elicitation interviewing was originally used by to study migration and the participants’ everyday lives in relation to technological and economic changes. Photo-elicitation involves using photographs to evoke participants’ memories and discussion during interviews and to explore their lived experiences (Harper 2002). Lived experiences are sometimes difficult to articulate, but participants can use photographs to anchor their thoughts on past, present, and future in relation to the research topic. An image produces multiple readings and messages, which are, according to Schwartz (1989), intrinsically ambiguous. However, this ambiguity should not be considered a limitation or disadvantage. On the contrary, when used to aid participants’ communication of complex messages, it may contribute to the generation of richer data.

Photo-elicitation has also been shown to reduce the power imbalance between the researcher and researched (Harper 2002). When images are produced by the

researcher, some level of distance between the participant and the researcher is generated. However, when participants bring or take their own photos, they are more able to direct the discussion, which is useful when exploring sensitive issues. Harper (2012) asserts that the world that is seen and represented visually is different from the world that is represented through words, and as a result, the former connects to different realities than more conventional research methods. In visual methods, drawings and photographs are not just passive images but symbolic representations of a structural order of things in society. For researchers, the use of visual methods uncovers the meanings embedded in these images. Below is an example of using Culture grams (Chang 2008), drawing, and sketch mapping with youth participants:

The various drawing methods were useful communication tools to elicit the participants' voices, which reflected their diverse sociocultural surroundings. Culture gram (Chang 2008) was used to help capture the young people's meaning of their cultural identity during the second and last interview. In understanding who they are, responses on their religion, ethnicity, interests, hobbies, strengths and weaknesses, and physical activity experiences were elicited. During the interviews, students were asked to draw or write down their responses to the questions on a piece of drawing paper alongside answering the interview questions. Students were also asked to circle the three most important characteristics that best represented themselves. This method enabled the students and me to visually see the responses and, thus, allowed the students to describe the possible interconnections among the different topics. In addition, preserving this vivid and visual detail of their commentaries allowed us to recapture the students' responses with reference to their own cultural gram after a year's time in the last interview. As for eliciting the research data, it helped to visually note that these young people's cultural practices were diverse and multicultural. Their drawings showed a colourful array of their experiences, capacities, and engagements. The data helped to challenge as well as respond to the binary understanding of "East" or "West" cultures. The use of a culture gram was new to research for understanding young Chinese people's engagement in physical activity, specifically in demonstrating their subjectivities in relation to their surrounding contexts.

In particular, the visual representation of drawings assisted in eliciting students' interview responses, as it allowed the young people and me to refer to the interconnectedness of the topics under discussion. The use of mapping their neighborhoods in Australia and overseas also provided an anchor for the young people, the readers, and me to visualise possible social and environmental differences and thereby understand and discuss why and how these young people live across two different cities or countries. By looking at two maps (i.e., Brisbane and their overseas contexts), these young people were better able to compare and contrast the facilities, weather, and spaces that were conducive to their physically active lifestyles. In addition, the drawings allowed us to visualize the perceived functionality of the facilities and the distance between the sites. For example, a number of the participants' drawings showed accessible recreational facility sites, such as basketball courts, parks, and shopping malls, while others suggested there were risks in using these sites, such as busy roads, steep slopes in the parks, and the intense sunshine.

4.2 Sensory Methods

We learn through our senses, and this sensoriality influences how we understand and represent others' lives. Pink (2009) discusses the use of the sensory approach to understand the complexity of people's meanings in the contemporary social world. For

example, researchers have been concerned with their own sensory embodied experiences in relation to researching their participants (Downey 2005). Sensory perceptions are central to researchers' encounters in fieldwork, including the sociality and materiality of the research. Some important groundwork on sensory methods includes the sensual and affective dimensions in space (Thrift 2004), perceptions and the environment (Ingold 2000), and cultural differences and senses (Howes 2005). In conducting sensory research, the modern Western five-sense sensorium can offer useful analytical categories through which to understand embodied knowledge and practice (Pink 2015). Researchers have focused on using various combinations of sight, sound, smell, taste, and texture to understand and represent participants' lived experiences. For example, a cold breeze will have an impact on how people feel about the social and physical environment and shape how they act in relation to others (as in Sunderland et al. 2012). Research has also drawn on other methods – for example, go along or walk-along interviews (Carpiano 2009; see ► Chaps. 72, “Walking Interviews,” and ► 73, “Participant-Guided Mobile Methods”), participatory video documentaries (Pink 2007), and photovoice narratives (Baker and Wang 2006; see ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method”) – to access local knowledge and sensory data from the research and participants. These methods are often participant-led and allow participants to share their experiences more naturally with the researcher.

Pink (2007) notes that ethnographic practice entails our multisensorial embodied interactions with others and the social, material, discursive, and sensory environment. Sensory researchers believe that human experience is mediated through the body and therefore our senses. This embodied experience is how we make sense of ourselves, others, and things in a place (Howes 2005; Pink 2009; see ► Chap. 61, “Innovative Research Methods in Health Social Sciences: An Introduction”). Therefore, human experience is not only embodied but also emplaced. As Merleau-Ponty (1964) describes, place is central to gathering people's experiences, histories, and things. In particular, sensory geographers considers how the specificity of place can only be understood through a zone of entanglement (Ingold 2008) constituted through lived bodies and things (Casey 2001). Research questions that can be used in sensory ethnographic methods in health and physical activity research include: *What does it feel to live and do physical activity here?* and *How can the rich sensory ethnographic accounts of lived experiences be used to influence health planning in this community?*

5 Opportunities and Perils of Using Ethnographic Methods

Based on the literature and research examples in the previous sections, there are some conclusions that we can make in relation to the opportunities and perils of using ethnographic research methods. One of the main advantages associated with ethnographic research is that it allows researchers to identify issues that arise during their ongoing interactions with participants (Atkinson et al. 2001). When conducting other types of studies that are not based on fieldwork and observations or more generally interactions, there is a lesser chance to introduce new topics within the broader research question under examination. This is because researchers are

encouraged to exercise their reflexivity during fieldwork and to probe further questions or change the direction of their research topics in response to the participants' responses and behaviors. Another main advantage of ethnographic research methods is that they aim to represent the detailed and authentic experiences of the insider. As a result of this intersubjective nature, an ethnographic study can be very useful in revealing in-depth and multisensory data about the participants.

One of the main criticisms of ethnographic research is the amount of time and effort that are required to produce trustworthy results (Atkinson and Hammersley 2007). The use of interviews, observations, and fieldwork within an ethnographic study requires a certain amount of time, and the results tend to take longer to generate. This is because understanding of a cultural practice takes time to unfold, and it takes time for the researcher and participants to make meaningful connections (Liamputtong 2010, 2013).

As stated above, the conduct of ethnographic research methods requires the researcher to be a participant in the observation within the environment. There are two main potential risks with using ethnographic methods. First, ethnographic researchers need to be skilled to minimize potential pitfalls, including the "thickness" of the data collected and potential bias, as well as a lack of reflexivity in data collection or analysis (Atkinson et al. 2001). It is also vital that the participants be willing and open with the researcher in discussing their lived experiences. As such, the quality of researchers themselves and their role in study design play an important part in eliciting responses from participants. As discussed, one of the most important criteria in ethnographic research methods is the researcher. This means an ethnographic researcher is critical to a study's success. Based on my research with young Chinese Australians in physical activity, I offer a few tips to researchers who may be considering using an ethnographic research methods approach to their study:

- Do not choose ethnographic methods or qualitative research only because you cannot do statistics.
- Do not expect there to be standard procedures.
- Do not regard your initial research plan as sacred.
- Do not leave analysis till the end.
- Do not take things or people for granted.

6 Conclusion and Future Directions

Ethnographic research methods entail an eclectic approach. They involve making connections between people's complex lived experiences and their ever-changing structural environments. In this chapter, I have suggested several key ethnographic research methods and examples of how to carry them out in research. I have also noted that human beings are both embodied and emplaced subjects, and that experiences, history, and things interact and accumulate in a place. In using ethnographic methods, researchers are interested in delving into the entanglement of these histories, cultures, and lived experiences. Words alone are sometimes insufficient to shed light on the

complexity of people's lived experiences in contemporary society (Banks 2008). Visual and sensory methods provide alternative means of conducting ethnographic research with participants. Working with images, unlike working with texts alone, encourages research to move towards sensory methods (Pink 2007). One of the tasks of ethnographic researchers is to develop an awareness and reflexivity of how they become involved not only in understanding participants' embodied feelings, experiences, and practices but also in reflecting on their co-involvement in the research, the place where the research takes place, and the interactions between the researcher and the researched. The success of ethnographic research requires a relational, flexible, and reflexive informed approach that acknowledges our multiple senses and embodied dimensions in relation to understanding people's lived experiences.

Rapidly advancing technology and increased globalization require innovative ethnographic methods to capture the socially networked and ever-changing living environments. Digitalization provides researchers with unprecedented opportunities for understanding and exploring people's lives. The increased use of social media as means of sharing information is creating opportunities for health and physical activity researchers to examine their participants and the data they generated online. This emergence of online ethnographic research methods such as netnography (Kozinets 2015) has allowed researchers to collect data on online communities and social media spaces such as blogs and twitters (see ► Chap. 75, "Netnography: Researching Online Populations"). Such approach moves beyond the limitations of quantitative survey methods that relies upon a participant's memory, and therefore increases the trustworthiness of the research findings (Costello et al. 2017). The emergence of new forms of digital cultures and methods will continue to shape the nature and practice of ethnographic research. For example, the use of "ethnomining," a way of joining ethnography and data base mining, attempts to collect big data in an online environment which is relatively cost-effective than traditional ethnographic research approaches (Varis 2016). Nonetheless, as Kozinets (2015, p. 97) reminds us, "the key element is not to forget the participative, reflective, interactive and active part of our research when using the communicative function of social media and the internet," which aligns with the purpose and practice of ethnographic research methods.

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Institutional Ethnography

27

Michelle LaFrance

Contents

1	Introduction	458
2	Key Terms for IE Inquiry and Analysis	460
2.1	Problematic	460
2.2	Institutions	461
2.3	Ruling Relations	462
2.4	Standpoint	462
2.5	Social Coordination	463
2.6	Institutional Discourse: Texts, Textual Mediation, Boss Texts, and Institutional Circuits	464
2.7	Work and Work Processes	464
3	Data Collection	466
4	Conclusion and Future Directions	467
	References	469

Abstract

Institutional ethnography (IE), a form of critical ethnography introduced to the social sciences in the late 1990s by Canadian sociologist Dorothy J. Smith, poises researchers to uncover how “work” (a concept defined generously) is co-constituted within institutional environments. The IE approach reframes institutional sites as dynamic shape shifters that use texts to mediate, organize, and lend value to the social practices of diverse and knowing individuals. Workplaces and practices can be said to reproduce the broader spheres of influence, prestige, and value that structure society at large. As such, IE seeks out the (often implicit and/or erased) connections between work processes and institutional discourses, revealing how work is coordinated across time and space. More plainly, the

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457

methodology uncovers *how things happen* – how institutional discourse compels and shapes practice(s) and/or how norms of practice speak to, for, and over individuals. IE research offers opportunities for more situated and finely grained understandings of the sites where we work, the people we work most closely with, the generative power of institutional texts and discourse, and the ways that our participation in work then gives material face to the institutions that govern the social world.

Keywords

Institutional ethnography · Ethnography · Feminist methodology · Cultural materialism · Standpoint · Material relations · Institutional discourse · Textual analysis

1 Introduction

Institutional ethnography (IE) is a form of ethnographic inquiry introduced to the social sciences in the 1990s by Canadian sociologist Dorothy J. Smith. Smith's career work critiques traditional models of social science research; these traditions relied upon positivist paradigms and universalist models of empirical observation and disinterested analysis, processes that many ethnographers claim overdetermine and reify research participants and the social realm (1974). Generalized understandings of institutions erase the actualities of lived experience for real people; Smith (2005) argues, flattening important disjunctions of doing, knowing, and being. The model of ethnography Smith has developed instead draws upon principles of feminist cultural materialism to focus the researcher's eye upon the unique personal experiences and practices of individuals. Feminist research methods draw on the notion that the personal is political and strive to bring forward stories of the marginalized, hidden, and overlooked as they affirm differences among people (DeVault and Gross 2012). Cultural materialists hold that the material actualities of a culture (social structures, infrastructure, economics, technology, the political, ideology) exert enormous power on groups and individuals; these structural forces (the macro) play an undeniable role in the organization of everyday life (the micro).

Institutional ethnographers locate a unique standpoint and engage in the research practice of "looking up from where [they] are" (Smith 2006, p. 5), a means of uncovering the highly situated and personal experiences and practices of individuals. This move is similar to what Laura Nader (1969) calls "study[ing] up," a process of inverting the power differentials that often inform ethnographic research. The goal of IE inquiry is to reveal how actual lives take shape as a process of negotiating social relations. Seeking to uncover the relationships between highly personal experiences and practices of active individuals and their everyday (material) contexts, according to Smith, reveals any number of stories and experiences that are often otherwise erased, elided, or ignored.

Ethnography is a ubiquitous methodology in many fields. Defined by Linda Brodkey (1987, p. 25) as "[t]he study of lived experience," by Laura Nader (2011,

p. 211) as a mix of descriptive and theoretical research that seeks “an emic perspective” (or “the insider’s point of view,” and humorously by Clifford Geertz (1998) as “deep hanging out,” ethnography offers an adaptable and reflexive means by which to explore the complex and highly networked topoi of everyday life. Originating from the field of anthropology, where it often focuses on participant observation and the intensive study of a community or social environment, ethnography offers a sense of richness and specificity that other forms of research, particularly those that seek patterns in human behavior or that view social organization from a disinterested distance, may not (see also ► Chaps. 13, “Critical Ethnography in Public Health: Politicizing Culture and Politicizing Methodology,” and ► 26, “Ethnographic Method”). Institutional ethnographers often position themselves as social activists whose research uncovers the experiences of actual people who carry out their work in neoliberal, so hierarchical and highly prescribed, environments.

While traditional ethnographers are often interested in what is happening – how what people are doing in a site offers insights into a particular social order, for instance – the IE project sets out to uncover *how things come to happen*, noting that “[p]eople participate in social relations, often unknowingly, as they act competently and knowledgeably to concert and coordinate their own actions with professional standards” (Campbell and Gregor 2002, p. 31). The methodology investigates how individuals within a location co-create the dynamics and processes that give the site its unique character. To understand what is actually happening within institutional sites, institutional ethnographers ask how experiences and practices are co-constituted in the moments that knowing and active individuals negotiate social, professional, and institutional systems as they carry out their “everyday/everynight” lives (Smith 2005).

Much recent institutional ethnography has been invested in exploring the ways people carry out their “work,” a concept defined generously (Griffith and Smith 2014). In IE, “work” denotes a series of coordinated practices within a local setting that an individual routinely puts time and energy into. It is through work that institutions coordinate the experiences and practices of individuals, particularly in “corporations, government bureaucracies, academic and professional discourses, [and] mass media,” highly structured social complexes that have an inordinate power over the ways people go about their everyday lives (Smith 2005, p. 10). The work at the center of an IE study might be paid labor, but it might also be forms of invisible work, such as the running of a household, unrecognized and/or unacknowledged activities associated with paid labor, or the activities of clients, patients, or other members of a community. Workplaces and practices are sites that reproduce the broader spheres of influence, prestige, and value that structure society at large. As such, IE seeks out the (often implicit and/or erased) connections between work processes and institutional discourses, revealing how work is coordinated across time and space.

The IE framework holds that work experiences and practices take shape in relationship to local materialities; work is always socially coordinated, rule-governed, and textually mediated. An example would be the ongoing historical construction of household chores as the work of women. Another example might be the problem-solving processes patients must go through in order to receive paid treatment under a particular insurance plan. Using IE to study the work that people

carry out makes visible the values, practices, beliefs, investments, and belongings that circulate below more visible or dominant institutional discourses and ideals of the everyday. To trace these mutually constitutive relationships, IE focuses the researcher on the practices people engage in, the decisions they make, and how their negotiations of values, policy, procedure, labor hierarchies, and work systems take on a particular shape. On the one hand, these everyday work experiences and practices are a matter of choice, personal forms of identification, and taste; on the other hand, because institutions are material locations and social relations have material implications, these everyday doings are often highly circumscribed by active social and professional norms. The doing, knowing, and being of people bring these tensions into visibility, making the institution itself legible for study (Smith 2001). Institutional ethnography, then, reveals the material actualities – what people do to negotiate the everyday – at the heart of our institutional existences.

2 Key Terms for IE Inquiry and Analysis

Several distinctive analytic moves are central to IE, lending focus to the institutional ethnographer's development of a dynamic and evolving protocol, data collection activities, and the analysis and interpretation of data: *problematic*, *institutions*, *ruling relations*, *standpoint*, *social coordination*, *institutional discourse*, and *Work*. Two concepts are central to the analysis of social sites that institutional ethnographers enact: “standpoint” and “ruling relations.” With both terms, Smith asks us to think about how the spectrum of social forces organize actual people, as well as how institutions regulate and bind individuals to ideals of practice. These moments of ethnographic inquiry collapse distinctions between broader discursive forces (such as professional and institutional discourse), beginning with the understanding that our everyday lives are discursively constituted. Individuals are unique, and knowing, but also act from places of shared identity, local belonging, professional alignment, and personal investment – their “standpoint.” “Ruling relations” are “that extraordinary yet ordinary complex of relations...that connect us across space and time and organize our everyday lives” (Smith 2005, p. 8). An IE project seeks to empirically trace the connections between these two points of understanding, noting that there is always a relationship between the “micro” and the “macro” elements of the sites under study (DeVault 2008, p. 4). The other terms offer insights into IE as a research practice and additional fine-grained understandings of how ethnographers may come to uncover elements of institutions, especially how their discourses coordinate people across time and space.

2.1 Problematic

An IE project begins with a problematic, a process of “research and discovery,” according to Smith (2005, p. 227). A problematic suggests a direction and/or a loose set of boundaries for an investigation, as it takes into account how experience and practice are situated within and contoured by discourse. A problematic is not

necessarily a “problem” in an organization, such as the problem of overtime for medical staff. Instead, a problematic exposes an overlap of competing ideals or calls attention to where institutional discourse and the particularities of lived experience refuse and resist one another. An example problematic might be a question, such as: What is the relationship between the policies of insurance companies and the language use of health-care providers when speaking with patients? A focus on a problematic entails the recognition that not all people experience a site in the same way and that practices, particularly work practices, will take shape in any number of ways as the efforts of knowing people are coordinated under the influence of institutional discourse, professional expertise, and personal predilection. The uneasy moments at the center of any workplace story often suggest that people within an institution are differently organized in relation to their daily work. Thinking of these differences in relation to the “problematic” of a workplace reaffirms that some practices within institutions will always be scripted for individuals, but that individuals will also actively negotiate and renegotiate these points of institutional contact in highly personal ways.

2.2 Institutions

“Organized around a distinctive function, such as education, health care, and so on” (Smith 2005, p. 225), institutions are complex rhetorical, social, and material entities, which house any number of diverse rule-governed, hierarchical, and textually mediated workplaces. The challenge for the institutional ethnographer is to recognize the dynamic and generative nature of the institution as a social entity. IE supports this move by conceptualizing individuals as unique and knowing, while emphasizing that institutions function as “shape shifters” (LaFrance and Nicolas 2012, p. 131), social constellations that take shape relationally around the distinctive needs and roles of the individuals who engage them. Institutions encompass multiple, dynamic experiences and a proliferation of practices. The institution is a site of dialogic and multivocal belongings, where actual people make visible their unique understandings of the institution and their roles within it.

Most people tend to have a “general macro-level idea” in mind when thinking about or discussing institutions and large formalized organizations (LaFrance and Nicolas 2012, p. 131). That is, we share a collective understanding of these sites based on common preconceptions and experiences in and around them (Smith 2005, p. 160). Think, for example, of a community hospital. The patient of a community hospital will have a different viewpoint of the hospital than will a medical professional employed by the hospital. One medical professional will have a different set of interactions with the hospital from other medical professionals who work in different areas of that hospital. As they interact with different people, different times, and locations, they will literally experience the hospital differently. Staff who do not carry out medical procedures will have a different set of working conditions and practices from professionals with other job designations. The family and friends who visit a patient will have a different view from those who are employed or are attended by the hospital. The private hospital that is only a few minutes away will have a

different (if also somewhat coincidental and similar) group of people seeking its services, sets of conditions for those who are employed by its offices, and discursive understanding of its mission or goals. It is easy to take these differences for granted; on their surfaces, these locations of work may seem quite similar. But the differences of experience, practice, and work are crucial to recognize and flesh out with specificity if we are to understand how institutions recreate the social order in line with regimes of power, prestige, and authority. Indeed, the institution of the community hospital can be thought to shape shift – taking on different qualities, providing different services, and responding differently to needs – based upon the unique standpoints of those who access this site. And, the relationship of the patient to the hospital will shape shift again once the patient has left the hospital or no longer needs its services.

2.3 Ruling Relations

As people act with purpose and knowledge, they act in coordination with professional standards and the expectations of organizations, colleagues, and employers. It is in this term that we see IE's most explicit nod to Marxist cultural materialism; as Marx (1852, 1913, p. 9) is known to have said: "Men make their own history, but they do not make it as they please; they do not make it under self-selected circumstances, but under circumstances existing already, given and transmitted from the past." This means that we must be careful to acknowledge that social relations do not simply happen to people; they are not accidents but rather the product of historical moments and the particularities of location. Working conditions and daily routines bear traces of ideology, history, and social influence. Akin to powerful social or workplace norms, ruling relations draw on complexes of power, authority, and labor – expertise, marginality, influence, and decision-making. This social landscape coordinates how actual people carry out their particular daily practices as they negotiate the everyday. As people act with purpose and knowledge, they act in concert with the expectations of organizations, communities, and employers. Participating in these forms of social organization naturalizes the multitudes of practices that imbue a site, entrenching certain practices into the cultural fabric, making them "just how it's done," "common sense," and/or easily taken for granted.

Ruling relations make themselves visible when we see over time and space how the work of one person (or a small group of people) bears similarities to the work of others in other locations. When we see researchers and practitioners share vocabulary, philosophies, routines, and regimes, or when those we interview independently tell the same stories, reflect on the same moments, discuss the same issues, or offer a shared sense of purpose, ruling relations are coming into visibility.

2.4 Standpoint

Smith's early career work aligned with other feminist thinkers who posed "standpoint theory" as a challenge to the universal or "pure" knowledge and positivism of

the sciences and social sciences. Smith's (1974, p. 22) arguments in "Women's Perspective as a Radical Critique of Sociology" critiqued masculinist models of sociology, which excluded women's experiences and perspectives from "methods, conceptual schemes, and theories." These models privileged abstraction, objectivity, and a disembodied subject, according to Smith, not only dominated, and so structured, mainstream sociological thought, but relegated women and the concerns of women "outside and subservient to this structure" (p. 26). The resulting paradigm erased and marginalized differences of experience, being, and knowing, restricting what could be known, studied, and understood. Other standpoint theorists, such as Haraway (1988), argue that knowledge is "situated" (1988), or as Harding (2004, p. 3) explains that "the social order looks different from the perspective of [the] lives and or struggles [of those marginalized by the social order]." Recognizing all knowledge as the product of a particular epistemological framework allows us to understand a richer range of experiences (Haraway 1988). Beginning IE projects from the unique standpoint of someone who carries out their work within an institutional setting is one way to come to know the particularities of experience and practice that give the institution its face. An embrace of standpoint allows us to uncover and tell the stories of people whose lived experiences may otherwise be elided, erased, or ignored.

2.5 Social Coordination

Social mechanisms sanction practices, granting some legitimacy; in this way, the social order comes to coordinate *doing, knowing, and being*. Drawing upon Marx and Engels' critique of the German ideologists, Smith (2005, p. 65) grounds IE in the argument that the social and people's activities mutually inform one another:

The social might be conceived as an on-going historical process in which people's doings are caught up and responsive to what others are doing; what they are doing is responsive to and given by what has been going on; every next act, as it is concerted with those of others, picks up and projects forward into the future.

Institutions in the IE framework, as such, are social entities created in the moments that individuals take up particular practices toward specific ends – institutions serve as "networks" or "complexes" that serve a distinctive function (education, government, health, entertainment), perpetually constructed and reconstructed (socially coordinated) through the active participation of individuals. This framework focuses ethnographers on tracing actualities of experience, especially "distinctive relational sequences" – *or how work gets done* – as these reveal the ways local cooperative efforts respond to and reinscribe broader economies of value (Smith 2005, p. 54). IE's focus on the social nature of institutions acknowledges that the work of individuals is coordinated in alignment with (or resistance of) a spectrum of different values, notions of expertise, ideals of belongings, and other factors. These complex interrelations between the individual and the social realm are always dynamic, evolving, and mutually constitutive within a site (Campbell and Gregor 2002).

2.6 Institutional Discourse: Texts, Textual Mediation, Boss Texts, and Institutional Circuits

Institutional discourse and texts are not just sources of information but shapers of experience and practice. Smith (2001, p. 100) writes that formalized discourses and texts have an “architectural significance” within organizations; institutions coordinate individuals across time and space through the vehicle of written and visual texts. To say this differently, the variety of different communications central to work and participation in the social order rhetorically influence what people do, sanction experience, grant agency and authority, and privilege certain practices over others. “Institutional discourse” operationalizes, organizes, and controls workplaces and how people carry out their work, creating generalizations, and so a sense of continuity, across individuals, practices, and sites (Smith 2005, p. 225).

IE’s emphasis on texts “emerges from empirical observation as well as from theory; it comes from the insight that technologies of social control are increasingly and pervasively textual and discursive” (DeVault 2008, p. 6). The power of texts particularly arises out of their replicability – they persist over time and space – and exhibits a seemingly fixed nature. As Smith (2001, p. 160) writes:

Texts and documents make possible the appearance of the same set of words, numbers or images in multiple local sites, however differently they may be read and taken up. They provide for the standardized recognizability of people’s doings as organizational or institutional as well as for their co-ordination across multiple local settings and times.

“Boss texts” carry a certain type of authority, determining experience and practice “in such a way that an institutional course of action can follow” (Griffith and Smith 2014, p. 12). As texts carry ideas, language, and elements of persuasion between individuals (even those with little personal interaction), they subsequently transfer ideals of practice and affiliation across sites. Likewise, through texts and textual practices, individuals are enabled to recognize, organize, and respond to processes of social coordination. “Boss texts” particularly act as forms of “institutional circuits,” which create ideals of accountability, professionalism, and disciplinarity, as they regulate – and often standardize – practice, mediating idiosyncrasies and variability in local settings. An example of a boss text would be the patient review form. The blank template is produced by medical professionals and their office staff; this form is used to evaluate patient needs, the services provided, and an array of other procedures from paperwork to medically oriented interactions.

2.7 Work and Work Processes

Much recent IE research has focused on the “front line” of public sector employee work, with the concept of “work” defined very generously. Because the term “work” is so comprehensive, it is somewhat difficult to define; but Griffith and Smith (2014, p. 11) note that:

In those institutional settings where services are provided to clients, we should remember that, using the “generous” conception of work, those who are served are also working; they put in time and energy and are active in actual local settings as they engage with or are caught up in an institutional process.

More generally, Smith (2005, p. 229) uses the term to refer to “anything that people do that takes time, effort, and intent.” As an analytic lens that focuses institutional ethnographers on what people do, “work” is one site where the actualities of experience and practice can be readily traced in the interplay between individual and broader systems of value.

Devault (2008, p. 6) explains that work *processes* are “[o]rganizational strategies. . . [that] highlight and support some kinds of work while leaving other tasks unacknowledged, to be done without recognition, support, or any kind of collective responsibility.” These processes ground the work of multiple individuals in conceptions of practice, providing the opportunity for the writing researcher to trace individual and institutional values in action. As “distinctive relational sequences” – *or how work gets done* – these processes reveal the ways local cooperative efforts respond to and reinscribe broader economies of value (Smith 2005, p. 54). We can understand “work” (in an office, in a clinic, one-on-one with a patient or client), then, as both a social collaboration and a product of uniquely personal understandings, preferences, identifications, and affiliations with and within particular institutions and disciplinary and professional identities. Devault (2006, p. 295) argues that institutional work life (experience and practice) is more tightly organized, regularized, and so coordinated, than in “households or family groupings, for instance,” where texts and discourses more closely align through institutional logics and other social mechanisms.

Uncovering how work processes take shape – who determines what will happen and how – reveals the influences, hierarchies, and organizing factors at work upon individuals as they go about their daily activities. The process of asking for disability accommodations is an excellent example of the power of work processes: individuals must fill out quite particular forms (typically approved in advance by a number of offices and/or individuals), with very particular types of information to be included. The types of information included on the forms will often index closely to the individual’s personal history. But, whether a person can be considered disabled or “qualifies” to claim a particular disability is a situation defined by governmental and health agencies; the criteria for consideration has been determined by medical, legal, governmental, and professional bodies in separation from the on-the-ground experiences of people who are living a unique array of embodied actualities. In many cases, the forms that document these experiences must be submitted for review to an office or committee of professionals (depending upon the local protocol), and the individual’s abilities and experiences are evaluated against a number of pre-established (and sometimes hidden) factors and criteria. Each of these steps is typically highly prescribed, so that a clinic, office, or an employer is in alignment with state employment disability and discrimination laws, local culture, and other expectations associated with the site. Of course, having a procedure for determining

disability does not mean that these processes are always entirely transparent, fair, or clear. The relationships individuals may have to these processes are crucial to note, as these will reveal the components of experience: the ways legal status, social status, and other factors, such as the personal philosophies, motives, and mutable practices, may become slippery as they move from a conceptual realm to be applied to a specific case.

Each of these interdependent terms related to the activities and practices people carry out as they go about their work focus the institutional ethnographer on powerful indicators of hierarchy, authority, and belonging within systems of work and labor, as they coordinate the practices of unique individuals across time and space. These key terms and analytic moves within the larger framework of IE allow us to explore the problematics of work from the standpoint of those who do the work, seeing experience and practice that may not be visible from other vantages.

3 Data Collection

Data collection for the IE project comprises observations, interviews, collection of documents, and other artifacts for analysis (see ► [Chaps. 23, “Qualitative Interviewing,”](#) ► [26, “Ethnographic Method,”](#) and ► [29, “Unobtrusive Methods”](#)). The institutional ethnographer seeks to bring to light an assemblage of experiences and practices through the course of a study; sites of study are recognized as locations of dialogic and multivocal belongings. The practices studied, the interactions, access of services, the creation of documents, and the carrying out of work, are read as moments of negotiation, where actual people make visible their unique understandings of the institution and their roles within it. The narrative produced presents a dynamic and multilayered understanding of lived experience and practice within the institution, often focusing on how people make choices, access resources, and participate in established routines.

Wright and Rocco (2016) argue that the IE project generally unfolds in two stages. Stage one begins with “fully understanding and developing the research [p]roblematic” (p. 28), by getting a sense of the contradictions and disjunctions of lived experience that are central to a particular set of social interactions. This process of observing the general experiences and practices of participants establishes the scope and specific focus of the study, as it offers the institutional ethnographer a sense of how things are happening, the ways the hierarchies of work coordinate how people do what they do, and other important aspects of the location. Once the institutional ethnographer has established an understanding of the standpoints central to the site, then the process of “looking up,” previously described, comes into play – what Wright and Rocco describe as “stage two.”

“Looking up from where you are” enables the institutional ethnographer to observe the particularities of a location, a recognition that how people are positioned within a site will often dramatically impact not only what people do but how they do it. Smith (2006, p. 5) argues that personal experiences (and so, work practices) express a social order; the institutional ethnographer then seeks an understanding of

how the particularities of the social within a location then coordinate how people do what they do and influence their experiences and practices. DeVault and McCoy (2006, p. 20) describe the process of IE inquiry in similar steps: “(a) identify[ing] an experience, (b) identify[ing] some of the institutional processes that are shaping that experience, and (c) investigat[ing] those processes in order to describe analytically how they operate as the grounds of experience.” As institutional ethnographers study a site, they begin to get a sense of the “language, thinking, concepts, beliefs and ideologies” that constitute a site (Luken and Vaughan 2005, p. 1604); these elements of the social realm are all clues to how the social takes shape in a specific setting. That is, how is the fluid constellation of values, identities, belongings, hierarchies, and claims to authority coming together to give a site, and so experience, practice, and work, a unique character.

IE as a framework for inquiry gains its rigor and systematicity from this process of “looking up” and teasing out the relationships between the individual and the social realm. As Campbell and Gregor (2002, p. 29) explain: “Analytically, there are two sites of interest [to the institutional ethnographer] – the local setting where life is lived and experienced by actual people and the extra-local that is outside the boundaries of one’s everyday experience.” When data collection activities have resulted in a reliable body of data, the institutional ethnographer will begin to analyze how individuals speak of and engage in their daily practices, thinking about how participant responses and practices reveal the ongoing coordination of activity. Variations, disjunctions, disagreements, or absences may reveal themselves in the rationales enabled by this process of “looking up,” as these complex moments tell a story about the ways in which personal experience and work practices have been reflexively contoured by the material and discursive conditions of the site (Campbell 2003, p. 4). The institutional ethnographer explicates the confluence(s) of individual experience, work practice, and dominant discourses at each location, demonstrating “an empirical bridge between local and particular processes,” as it brings to light the ways in which individuals actively negotiate the “social relations that order everyday existence” (Luken and Vaughan 2005, p. 1604). Brotman (2000, p. 109) has described this process more succinctly as establishing a “gaze on the macro structure from the micro level.”

4 Conclusion and Future Directions

Institutional ethnography extends and reframes the work of the ethnographer, posing a line of inquiry that uncovers the relationships between the social realm and how people do what they do. Some have argued that ethnography’s explicit attention to lived experience and the social nature of practice offer a rich and varied understanding of the everyday that cannot be captured from disinterested forms of empirical study. Ethnographic study has been a go-to for researchers who hope to offer a human face to social issues and to offer a personal understanding of how public policy, social norms, and cultural experiences unfold for real people in real time and space.

Even so, a number of critical challenges to ethnography have been given voice since the mid-1990s. Hammersly (2006, p. 2), for instance, has called into question the “[legitimate] claim [that ethnography factually] represent[s] an independent social reality.” Others, such as Lubet (2018), question the veracity of the evidence collected by ethnographers. Arguing that ethnography suffers from a lack of fact checking, cross-examination, and the presentation of counterevidence, Lubet suggests that ethnographers must be more conscientious about whether their research narratives present reliable and *factual* representations. A number of others have claimed that ethnography relies too much upon the assumptions and observations of a single researcher (Kawulich 2005), cannot be replicated (LeCompte and Goetz 1982), and has not yet established a clear and systemic taxonomy of research practices (Wall 2015). These particular arguments retrace long-standing arguments in the social sciences, humanities, and the tradition of qualitative research about the nature of interpretation, analysis, and representation in research activities, how knowledge is constructed, and how study of the social achieves reliability.

In response to these critiques, ethnographers have adapted and evolved their stances, seeking models such as IE which have a central set of scalable and adaptable, but also somewhat regularized, analytic moves and a shared objective. These conversations gesture to the importance of situating chosen methods and methodologies firmly in an ontological and epistemological reflexivity, offering models of research that are positioned within areas of our research interest but that also methodologically extend and deepen our understandings of research practice as a local and grounded endeavor. IE does not seek to pose the researcher as an independent and so impartial observer, but rather to reveal that how people talk about work, experience, and practice is itself a negotiation of the norms of power and persuasion in a site of study.

Institutional ethnography is keenly attuned to helping researchers uncover aspects of experience and practice that other methodologies might not. Through its focus on the individuals carrying out the work of their institutions, the IE framework enables us to answer current calls in many fields to uncover how what we do in our everyday lives and as workers is coordinated by ideological and political discourses. IE enables us to systematically study the hierarchical systems of labor, professional systems of value, and notions of expertise and prestige that structure our local actualities. Through its lenses we are able to uncover stories that are often elided and that speak to the important actualities of everyday life. Cumulatively, these studies contribute to a broad picture of the discursive and organizational regimes of our lives. Ruling relations are so pervasive and so often “naturalized,” most of us are not always aware of how these social forces have structured our lives, our work, and our relationships. IE allows us to explore the dynamic facets of the everyday and to discover how what we do as workers, as people with full lives, is coordinated in alignment with the lives, the practices, and the work of others.

While IE has deep roots in the field of Sociology, it has now spread to a number of other fields: nursing, psychiatry, public health, occupational therapy, and many others. Those who use IE are continuing to evolve the ways that the framework for discovery supports a range of research endeavors related to uncovering the

hidden experiences of work and institutional knowing, being, and doing. Because so much about how people carry out their social lives is undergoing radical change in the twenty-first century, the result of transformations in innovation, technology, the shrinking of the public sphere, and the nature of organizational life, those interested in how actual people are negotiating these emerging contexts have found IE an invaluable tool. Many who study the global economy and neoliberal logics that drive commerce and other social forms of organization have commented upon the rise of accountability, measurement, efficiency, and adaptability as pressures structuring the global workforce. IE is being used to study how workers are coordinated by these emergent landscapes of labor. Future work with IE in many fields will continue to explore how people negotiate the everyday experience within these dynamic and global contexts.

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Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis 28

Sarah J. White

Contents

1	Introduction: Why Use Conversation Analysis	472
2	Methodology	473
2.1	Beginnings and Development of CA	473
2.2	Fundamental Assumptions and Methodological Foci	474
2.3	Institutional Interaction	475
3	Data Collection	477
3.1	Data Collection in Health Contexts	477
3.2	Recording	477
3.3	Transcription	478
4	Data Analysis	479
4.1	Unmotivated Looking	480
4.2	Systematic Analysis	480
4.3	Validity	480
4.4	Interactional Phenomena and Building Collections	481
4.5	Furthering the Analysis	482
5	Application	483
5.1	Key Findings in Health Care	483
5.2	Applied CA	484
6	Conclusion and Future Directions	485
	Appendix: Transcription Notation	486
	References	487

Abstract

Conversation analysis is a qualitative research methodology with roots in sociology, and, in particular, ethnomethodology. Over the past 50 years, it has developed not only within sociology but across the fields of linguistics, anthropology, and psychology. In health care research, conversation analysis has been successfully applied

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471

in researching interactions in primary care, surgery, pediatrics, and psychotherapy, to name a few examples. Conversation analysis allows the researcher to analyze the structures of interaction at a micro level, focusing on how the participants make sense of each other in conversation through shared interactional norms. In this chapter, I begin by surveying the history and development of conversation analysis. I consider methods of data collection and explore aspects of analysis in everyday conversation and in institutional interaction. I review key conversation analytic research in health care and consider its application and use for health care researchers.

Keywords

Conversation analysis · Qualitative · Interaction

1 Introduction: Why Use Conversation Analysis

Conversation analysis is the detailed microanalysis of talk-in-interaction, examined in order to provide insight into the structures of action that are usually (or normatively) oriented to by conversational participants. If the goal of the research is to understand how people are doing things using talk, like seeing a doctor, conducting a multi-disciplinary team meeting, or working in an operating theatre, conversation analysis allows researchers access to do so through its detailed and methodical approach.

The structure of conversation ensures that the production of social actions is both achievable and intelligible. Much of everyday sociality, both personal and institutional, is manifest through conversation (Heritage 2004). As Silverman (2001, p. 161) emphasizes, “conversation is the primary medium through which social interaction takes place.” Children are socialized through conversation (Heritage 1984), and, following Schegloff (1987), Clayman and Gill (2004, p. 589) note that it is “the primordial site of human sociality and a fundamental locus of social organization in its own right.” Not only is social interaction of the mundane variety managed through conversation, but so are the institutions that make up society – government, law, education, and health.

Communication is an integral part of the delivery of health care (Drew et al. 2001). From clinical handover (e.g., Jorm et al. 2009; Roger et al. 2016) and working in teams in the operating room (e.g., Mondada 2016; Yule et al. 2006) to eliciting patients’ concerns (e.g., Robinson 2006) and delivering diagnoses (e.g. Maynard 1992), much of health care is performed through talk-in-interaction. It cannot be emphasized enough how central communication is to the delivery of safe and effective patient care.

There have been two major methodological categories used in researching clinician-patient interactions: process analysis and the microanalysis of discourse (Heritage and Maynard 2006a, p. 2). Conversation analysis (henceforth CA), which belongs to the latter group of these methodologies, has been applied to primary care interactions (e.g., Heritage and Maynard 2006b), surgical interactions (e.g., Hudak et al. 2009; White et al. 2014), psychotherapy (e.g., Peräkylä 2008), nursing care (e.g., Jones 2003), physiotherapy (e.g., Parry 2004), mental health (e.g., Pino 2016), and much more. Arguably, the most effective way to understand what is occurring in a conversation is to record it and analyze it, and CA allows you to do just that.

CA does not focus on the *why* of social action, but on the *what* and the *how* (Clayman and Gill 2004), which differentiates it from other microanalytic methodologies. It is directed at finding patterns in conversational structure and understanding and explaining their logic (ten Have 2007), describing existing structural patterns to which participants orient their production and understanding of talk-in-interaction. In short, CA is “centrally occupied with describing the procedures and expectations through which participants produce and understand ordinary conversational conduct” (Heritage 1984, p. 245) and, as applied to institutional talk, “how ordinary talk is adapted or modified to accomplish specialized tasks and achieve the visibility of these social contexts, and how participants orient to institutional identities and entitlements” (Gill and Roberts 2013, pp. 575–576).

In this chapter, I begin by contextualizing this methodology through an exploration the origins, the fundamental assumptions, and methodological foci of CA. This is followed by two sections on how to do CA, separated into data collection and data analysis. To finish, I examine the application of CA, what we have learnt so far from the method, how it can be used, and what the future directions are.

2 Methodology

2.1 Beginnings and Development of CA

Conversation analysis was developed during the 1960s and 1970s, primarily by Harvey Sacks with Emanuel Schegloff and Gail Jefferson (Heritage 1984). Some of Sacks’ theorizing about how to study everyday social life can be traced to the work of his theoretical predecessors, Goffman and Garfinkel and, in particular, a field of sociology called ethnomethodology (Heritage 1984; Maynard 2012). Yet, his development of CA was new and remarkable. While not having a particular interest in language per se, Sacks found organization in the apparent chaos of conversation, demonstrating an underlying orderliness that had previously been thought impossible to describe (Heritage 1984). The focus of Sacks (and of CA in general) was form over content – the machinery of talk that allows participants to produce social actions (Silverman 1998). Sacks’s unique thinking formed a new theoretical framework, aiding in the development of a new way of understanding conversation.

In the seminal paper, *A simplest systematics for the organization of turn-taking for conversation* (1974), Sacks, Schegloff and Jefferson describe and analyze how people take turns in conversation, evidencing that talk is locally managed and structurally organized through norms that govern conversational practice. This paper, which has been cited over 15,000 times, also established the systematic and scientific method of CA. Unfortunately, Sacks had an early death, leaving it to others to continue the development of this field, in particular Schegloff and Jefferson, the latter developing the widely used transcription systems used in CA (Jefferson 2004). The transcription notations used in this chapter are based on Jefferson’s system (see transcription notation at the end of the chapter).

Conversation analysis has since developed considerably within a number of fields, including linguistics, anthropology and psychology (Gardner 2004) and has had substantive and methodological influence over these and other disciplines (Heritage 1984; Maynard 2012), as the advantages of examining naturally occurring data have become apparent. While CA is congruent with other observational research methodologies (Clayman and Gill 2004), it goes beyond such observation, as it provides analysts with the opportunity to repeatedly observe interactional phenomena. The advantage of this is the ability to discover fine details of interactions that would remain hidden without this methodology and it has been shown that such fine detail can have huge effects (e.g. Heritage et al. 2007). Aspects of CA can be found across different methods, such as the close analysis of recorded data and its “quantification” in building collections of interactional phenomena (Clayman and Gill 2004).

2.2 Fundamental Assumptions and Methodological Foci

In the recent collection, *The Handbook of Conversation Analysis*, Stivers and Sidnell (2013, p. 2) describe five key stances that coalesce to create CA: “(i) its theoretical assumptions, (ii) goals of analysis, (iii) data, (iv) preparation of data for analysis, and (v) analytic methods.” Throughout this chapter, I explore each of these, showing how they work together to create the distinctive methodology of CA.

In analyzing conversation, the analyst is assuming that conversation is orderly and that orderliness is able to be studied (Sidnell 2013). When people talk, they are orienting to a set of norms so that they can construct the conversation together. As participants in a conversation, they can take turns, they can respond in a way that makes sense, and they can repair the conversation if it stops working, among many other things. The analyst approaches conversation with a view to the participants’ understandings and orientations to the talk, rather than attempting to describe motivation, to which we have no access (Mondada 2013, p. 42). The focus is how interaction and intersubjectivity are achieved through the structures of talk.

There are three central methodological foci in CA (Silverman 2001): the structural organization of talk; its sequential organization; and the empirical grounding of its analysis. Each of these, briefly described here, encapsulate the principal findings of CA and the ways in which such findings are evidenced.

2.2.1 Structural Organization

The structural organization of talk is accomplished through the turn-taking rules (Sacks et al. 1974). These “rules” provide a normative guide that participants follow so as to maintain order within conversation; turns are managed by the participants in the conversation turn-by-turn with reference to these rules (Heritage 1984). While these are not necessarily consciously followed, they become apparent to speakers when the “rules” are broken. In the case of turn-taking, this would be, for example, when a speaker is interrupted by another party. When there is a momentary “break down” in the turn-taking organization, such as an interruption, this is when participants generally become aware that the structure exists as it is not being followed. It

then may (or may not) be addressed within the conversation. Analyses of such “deviant cases” are often used to demonstrate the existence and architecture of the structure of the conversation in question (ten Have 2007).

The structural organization of talk is further managed through a system of repair. Repairs are not concerned with the correction of “errors” in conversation, but instead aid the flow (or progressivity) of conversation when there are difficulties of speaking, hearing or understanding (Schegloff 2007). If there were no system of repair, there would be no way for conversations to progress if there were any such problems, thus completely halting conversation or at least making it mutually unintelligible.

2.2.2 Sequential Organization

The conversational structures and practices which are described by CA are those that make social interaction and mutual understanding possible (Heritage 2004). Conversation analytic research has demonstrated that context is created and maintained at a local level by the participants and that the creation of meaning is reliant on the sequential environment of the talk (Heritage 2004). Sequential organization forms the basis of understanding in conversation through this turn-by-turn building of context. Participants in conversation operate under the assumption that what is said relates to what has been said just prior (unless something is said to show participants that what is being said is not to be understood with reference to the prior talk (Sacks et al. 1974)), thus creating a contextual environment for mutual understanding and intersubjectivity (Heritage 1984). Heritage (1984) regards turns as both context-shaped and context-renewing; that is, turns are delivered with reference to the previous turn and they create a context for any subsequent turn. Thus, when analyzing conversation, it is essential to have access to the surrounding talk to the utterance(s) under examination, otherwise the analysis will be limited (Silverman 1998).

2.2.3 Empirical Ground of Analysis

Any claim in conversation analytic research must be supported by actual examples found in natural conversation. Therefore, CA is rigorous in the collection of data and its analyses (Clayman and Gill 2004). This is why conversation data is audio or video recorded to ensure the empirical soundness of the analysis. Heritage (1984, p. 237) notes that “it can be difficult to treat invented or recollected sequences as fully persuasive evidence for analytic claims.” Invented examples of talk based on the intuition of analysts are not a reliable source of data (Clayman and Gill 2004). On the other hand, recorded naturally occurring data exists independently of the analyst’s intervention and gives access to conversational practices akin to those experienced by the participants themselves (Clayman and Gill 2004).

2.3 Institutional Interaction

In studying institutional interactions, CA provides access to the normative structures and constraints to which participants orient their talk as they work toward common

institutional goals. By using CA, it is possible to understand how participants modify mundane conversational practices to achieve institutional outcomes. Conversation analytic research has found that in institutional interactions the practices of ordinary talk are modified and specialized for “task-oriented institutional contexts” (Clayman and Gill 2004, p. 592).

According to Drew and Heritage (1992, p. 22), there are three key concepts that differentiate institutional interactions from mundane conversation:

1. Institutional interaction involves an orientation by at least one of the participants to some core goal, task, or identity (or set of them) conventionally associated with the institution in question. In short, institutional talk is normally informed by *goal orientations* of a relatively restricted conventional form.
2. Institutional interaction may involve *special and particular constraints* on what one or both of the participants will treat as allowable contributions to the business at hand.
3. Institutional talk may be associated with *inferential frameworks* and procedures that are particular to specific institutional contexts.

There have been various methodologies used in the analysis of institutional interactions. These range from coding (e.g., Roter 1977) to CA (e.g., Drew and Heritage 1992; Heritage and Maynard 2006b), with many other methods in between. Quantitative methodologies have proved useful in this area, particularly when combined with qualitative research (e.g., Heritage et al. 2007); however, qualitative research gives more in-depth insight into the structures of the interactions. By using CA to research institutional interactions, we can see how everyday conversational practices are employed and modified for institutional purposes (Heritage 2004). It shows how members “invoke a particular context for their talk” (Silverman 1998, p. 171). Because CA is a very detailed method of analysis, it provides a comprehensive examination of the interaction and as such is a useful methodology in the study of institutional interactions. Through CA, analysts can, for example, explore how the roles of the professional and the layperson are co-constructed through the interaction, and how and why participants structure their conversational turns in the way they do.

In CA, as noted above, analysts use recorded data and, therefore, the details of institutional interaction are not lost as they are in observations, interviews, and experimental research (Heritage 1984). It involves the analysis of actual observable occurrences rather than invented or reported ones (ten Have 2007). Recorded data also has the advantage that the data are “neither idealized nor constrained by a specific research design or by reference to some particular theory or hypothesis” (Heritage 1984, p. 238). By using CA to study institutional interaction, the identities are made relevant and observable in the aims and activities of the participants involved (Drew and Heritage 1992).

Having explored the background and assumptions of CA, including its data-driven approach, I now move to describe the two primary aspects of conducting conversation analytic research – data collection and data analysis.

3 Data Collection

3.1 Data Collection in Health Contexts

Prior to recording interactional data, work must be done to adequately address the ethical, practical, and relational aspects of data collection (Parry et al. 2016). Collecting interactional data in a health care setting requires building trust with those from whom you are collecting it and that can be assisted through careful consideration of how you will ensure the privacy and security of the data (see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”). In planning your research, you can consider the following questions:

- Is this the best method for what you are wanting to understand?
- What “controls” will you include in your study design (e.g., participant profession, level of training, interaction type, etc.)? (Robinson and Heritage 2014)
- How will privacy be maintained? Will the data be anonymized or de-identified and how will this affect the way in which it is presented?
- How will the data be stored securely?
- How will the data be managed? (Jepson et al. 2017)
- Who will have access to the data? What are the governance protocols?
- What are you wanting to capture?

It is advised that you engage in proto-analytic ethnography (Mondada 2013, p. 42) prior to recording to gain a sense of what should be recorded. This involves observing the environment and interactions that you intend to record in to familiarize yourself, which will assist in defining the context of what you will be recording and the scope of the project. CA is well suited to collaborative research, thus involving participants who are familiar with these aspects (such as clinicians and/or patients) in the study design (and even the analytic process) can assist you in your planning.

3.2 Recording

The naturalistic stance of CA influences data collection, with a preference for capturing as much of the interaction as unobtrusively as possible (Mondada 2013) and video recording provides other contextual information beyond that which can be elicited from audio recording alone (ten Have 2007). The approach of CA prohibits the analyst from inventing and manipulating data and ensures a strong, empirical, and accountable basis for any conclusions drawn from it (Schegloff 1988). The increasing concerns around the ethical collection of data has meant that in most places anyone being recorded must be told in advance, though the various laws regarding this differ by jurisdiction. This means that the data might be affected by the consciousness of the participants that their conversation is being recorded. However, as Mondada (2013, p. 34) argues “(c)ontrary to what is often suggested... the camera, although permanently present, is not omni-relevant for participants, and

moments in which they do orient to it can be identified and studied.” More specifically, the natural, unconscious structures in conversation seem to be generally unaffected; the effects of using video and audio recording equipment are minimal on the conversational structures that are the focus of CA as the effects are generally limited to content rather than form (Clayman and Gill 2004).

There are a number of key considerations in the collection of video data as discussed by Mondada (2013, pp. 39-41):

- Perspective choices
 - Field size
 - Camera placement
 - Focus
 - Static vs. moving shots
- Technical choices
 - Cardioid vs. omnidirectional microphones
 - Lenses
 - Level of portability (with reference to setting)

These considerations form part of your study design and should be evaluated throughout the data collection process. Mondada (2013) and ten Have (2007) both provide practical details of the data collection process.

3.3 Transcription

Once the data is collected, the analyst then transcribes it. It is important to remember that transcriptions are not the data itself, but are used to make the original data accessible for in-depth research (ten Have 2007). The way a conversation is transcribed can affect the interpretation of the data as each transcriber hears and transcribes different elements of a conversation (Silverman 2001), so it is important to have the audio and/or video accessible during the analytic process.

Transcripts make the recordings more accessible to repeated analysis by visualizing the talk (and sometimes non-verbal action) into written text (Clayman and Gill 2004). Ideally, analysts should do at least some transcribing of data themselves (Clayman and Gill 2004), whether it be one or two whole transcripts from a collection or the fine-tuning of basic transcripts made by others (I have used both processes in my own research). The number of hours of conversation, the number of interactions recorded, and the focus of the analysis all affect how much will be transcribed.

The use of detailed nature of transcription in CA is motivated by the idea that no detail, no matter how minute, can be dismissed as being “disorderly, accidental or irrelevant” (Heritage 1984, p. 241). The transcripts preserve sequential detail of talk (Hepburn and Bolden 2013), including overlaps, pauses, and continuers, which, given the analyst is concerned with describing how people co-construct conversation, is important to maintain in the representation of the recorded data.

Transcriptions can also include nonverbal aspects of the conversation, included through transcriber commentary presented in double parentheses or through a set of symbols (Hepburn and Bolden 2013). To see what a CA transcript looks like, consider Excerpt 1. In this interaction, the patient is waiting in the preoperative area for surgery. The surgeon has come in to discuss the procedure. This excerpt is from the end of this discussion.

Excerpt 1 MQ-CARM12–14 (White 2015)

1	S:	\$we'll see i'll see if there's there's still\$
2		any evidence. alright, (.) well look we'll fly
3		into it.
4	P:	okay =um (.) tanya said can (.) one of you guys
5		give her a ca:ll [when it's done.]
6	S:	[yeah:: i can.] and i
7		should have her numbah? [but >but=
8	P:	[yeah
9	S:	=you have it on the top of y [ah
10	P:	[>it's on the
11		system.<
		((omitted 30 seconds regarding post-operative call))
12	S:	alright, (0.2) so (1.0) fly into it. (.)
13		[(very good)]
14	P:	[(do a good job)] heh [heh heh]
15	S:	[okay:] thank you.

In Excerpt 1, different details within the transcript can be seen, such as the square brackets which indicate where overlapping talk between speakers occurs (e.g., lines 5 and 6), pauses measures to the tenths of seconds (e.g., line 12), and turn-final pitch movement shown through different punctuation marks (e.g., line 3). Creating such a transcript takes time and through the repeated exposure to the data that is required in the very detailed transcription and by being forced to listen in much more detail than usual, one begins to notice different phenomena within the data (ten Have 2007). This makes transcription stand somewhere between being part of the data collection and the data analysis in its role as an analytical tool in CA. In the following section, I further explore the analytic process.

4 Data Analysis

There are two primary ways to approach interactional data: unmotivated looking and analytic keys.

4.1 Unmotivated Looking

The first of these involves the analyst noticing phenomena through repeated exposure to data either through transcription or through multiple plays. These inquiries are unmotivated insofar that they do not look for a specific feature but “discover” what features are present within that particular interaction and are open to discovering new features as well. Analysts “approach data without a specific agenda in mind at the outset, and thus remain open to previously unexplored practices of interaction” (Clayman and Gill 2004, p. 596). While the methodology of CA encourages analysts to start their inquiries with “unmotivated looking” (ten Have 1999), the nature of CA nowadays means that analysts have already been exposed to the theories and findings of previous research and are, thus, influenced by these theoretical notions when beginning their research. Entirely unmotivated looking is an unattainable ideal (Clayman and Gill 2004) and, as ten Have (1999) notes, it would be impractical to ignore the conceptual apparatus already built by CA research over the past several decades. However, we can view unmotivated looking as an open-minded and inductive approach to analysis.

4.2 Systematic Analysis

Another way of analyzing data within CA is systematic analysis which involves transcribing a sequence and then analyzing it systematically using previous principal findings in CA to “unpack” the sequence. This assists the analyst in finding patterns in the data. Many of the more recent studies have used the principal findings of CA to help begin their research and identify patterns in conversation. Ten Have (1999, pp. 107–108) provides an analytic package as an example of the systematic analysis of a natural recording using a detailed transcript. To summarize ten Have’s method:

- (a) Analyze a selected piece of data systemically, working turn-by-turn, explicating the use of the following “organizations” of conversational structure:
 - Turn-taking
 - Sequence organization
 - Repair
 - Turn construction/design
- (b) Formulate general observations about the specific piece of data, taking note of features of particular interest.

4.3 Validity

No matter which method of analysis (or combination of methods) is used, all analyses in CA are data-driven and come from naturally occurring interactions. Ten Have (1999, p. 103) summarizes “three distinct elements” from Schegloff (1996), which

relate to the assumptions and foci described earlier in the chapter, that are ideal in the empirical account for conversation analytic explications of actions:

1. “A formulation of what action or actions are being accomplished”
2. “A grounding of this formulation in the ‘reality’ of the participants”
3. An explication of how a particular practice, i.e., an utterance or conduct, can yield a particular recognizable action.

Both of the analytic approaches described above allow for the validity of claims through these empirical accounts. Peräkylä (2011, p. 415) summarizes the different ways in which validation is achieved in CA as: “[T]ransparency of analytic claims; validation through ‘next turn’; deviant case analysis; questions about the institutional character of interaction; the generalizability of conversation analytic findings; [and] the use of statistical techniques.” While not all of these aspects are present or used in every analysis, the inclusion of these within the analysis is central to the validity of claims made (c.f. Peräkylä 2011 for a detailed explanation of validity in CA research; Sidnell 2013).

4.4 Interactional Phenomena and Building Collections

Sidnell (2013) describes the analytic process as moving from noticing a potential phenomenon occurring more than once to then deliberately searching for and collecting examples of that phenomenon. In doing so, the analyst focuses on the position and composition of the phenomenon, casting a wide net initially to ensure nothing is missed. This approach to collection building works for both unmotivated looking and more systematic analysis using keys.

In creating a collection of a particular phenomenon, “one should include not only those that appear to be clear instances of the phenomenon in question, but also less clear boundary cases in which the phenomenon is present in a partial or imperfect form, as well as negative or ‘deviant’ cases where the phenomenon simply did not occur as expected” (Clayman and Gill 2004, p. 601). Deviant cases can often prove the “rule,” or systematic practice, that is under observation as participants will often orient to normative practices in deviant cases. Such cases strengthen the analytic explication of a phenomenon by broadening its scope and clarifying its boundaries (Clayman and Gill 2004). When the normative orientations of participants are not adhered to, participants will often account for such deviations; this is because this framework of normative orientations also means deviations are normatively accountable (Heritage 1984).

To exemplify the analytic process, let us revisit Excerpt 1. As noted above, this is an excerpt from a conversation between a surgeon and patient. In this excerpt, the surgeon is beginning to close the consultation, which is a preoperative discussion.

From an overall structure perspective (Robinson 2013; White et al. 2013), we can see this is nearing the end (or possible end) of the consultation. This is not only

because we have access to the full recording, but also because the participants are orienting to the end of the conversation. There is evidence for this beginning in lines 2–3, where the surgeon announces that the next activity will start soon by saying “we’ll fly into it.” We can also see that the patient orients to this being the closing as he pauses the closing by bringing up something new that he wanted to mention prior to the end of the conversation, that his wife wanted the team to call her after the surgery (lines 4–5). This starts a longer discussion at the end of which the surgeon partially recycles his announcement of moving to the next activity with “fly into it” in line 12. The patient accepts this and the conversation ends (for more analysis of this excerpt, see White 2015).

As an analyst, you could consider the whole interaction with the aim of noticing a phenomenon and building a collection. Alternatively, you could choose from the outset to focus on part of interaction, such as closings, to understand how they are constructed across a data set. You could even use what is known about a phenomenon to develop a broader trial, such as Robinson and Heritage (2014) describe (more on intervention studies below).

4.5 Furthering the Analysis

There are two routes to consider in furthering and presenting the analysis: single case analysis and analyzing practices of action (Robinson 2007). These are not alternatives, but rather the latter builds on the former (Schegloff 1993). The analysis still involves the close, detailed analysis of talk and requires an inductive and rigorous approach to ensure quality of the analysis.

A single case analysis involves the description of a single case or series of single cases when a phenomenon has been identified. Although it is referred to as “single case,” often examples from other cases from a collection will be referenced in that analysis (Raymond 2017). Single case analyses are useful for smaller collections, such as for newly described phenomena or rare phenomena (see also ► Chap. 19, “Case Study Research”). Analyzing practices of action involves larger collections of the phenomenon that often also include borderline and deviant cases as well as a significant core collection.

CA, in some respects, bridges a divide between qualitative and quantitative research. From its early days, there has been an emphasis of building collections of phenomena, allowing for the identification of context-independent practices. As Sidnell (2012, p. 90) notes, “we want to identify a phenomenon that happens often enough to allow for a collection to be made.” There is continued debate in the field as to how many instances of a phenomena in a collection are required to identify a conversational practice (Albert 2017). Schegloff (1996) suggests 60 instances within a core collection, while Robinson (2007), following psychological research, notes that a core collection of a practice (excluding borderline or deviant cases), needs at least 87 cases for statistical analysis.

One reason this debate continues is that numbers are in some ways irrelevant in CA. This relates the concept of “order at all points,” where since the participants are

able to make sense of each other, then it follows that they are able to do so due to adherence to the same norms (Sidnell 2013). Thus, choosing where to look or what to look at can also be considered unimportant, as “if... the way people organize their talk-in-interaction is ‘orderly’... then it does not matter very much which particular specimens one collects to study that order” (ten Have 1999, p. 50). That is, any episode of talk-in-interaction will elucidate something about the orderly, normative structures of conversation. However, when using CA to consider a particular institutional setting, for example, an analyst deliberately restricts their data sample to those from that setting so as to concentrate on how the structures of conversation are used in that setting (Silverman 1998). Deciding whether you approach it as a single case analysis or analyzing practices of action would usually occur during the analytic process, depending on what you find.

5 Application

In the final section of this chapter, I describe some of the ways in which CA has already been used to improve communication in health care and consider future directions.

5.1 Key Findings in Health Care

Around 40 of the last 50 or so years of conversation analytic research has involved a specific focus on health care interactions. The research, as noted in the introduction to this chapter, has covered a wide breadth of clinical interactions and continues to do so. In their chapter on CA in medicine in *The Handbook of Conversation Analysis* (2012), Gill and Roberts identify three streams of research in CA in health care (pp. 578–9):

- Physician-patient interactions
- Interactions between patients and other health care professionals and paraprofessionals
- Interactions among health care professionals

The aims of such research, according to Gill and Roberts, is “to understand and document *what* social actions and activities are accomplished by participants in medical encounters and *how* participants use interactional resources and sense-making practices to accomplish their goals, with the aim of identifying recurrent practices of interaction” (p. 577; italics in original). There have been hundreds of studies applying CA to clinical interactions and this research has resulted in findings that allow us to better understand how patients participate in decision-making, how clinicians ask questions, how people work in teams, to name just a few. Heritage (2011), for example, identifies three areas in which findings from CA research could be used to improve clinician-patient interactions and from this recommends training to assist clinicians in understanding how conversational norms can impact the

clinical encounter. What CA studies into communication in health care show is that through these interactions the participants are demonstrating their roles and identities (e.g. patient, doctor, nurse), establishing relationships, and accomplishing the activity at hand (Gill and Roberts 2012, p. 581).

5.2 Applied CA

The term applied CA has been used to describe both CA that involves focusing on specific interaction types or environments (as opposed to analyzing the talk without reference or specific consideration of the context) and to intervention-type studies. Antaki (2011) describes six types of applied CA studies (pp. 3–9):

- Foundational applied CA
- Social-problem applied CA
- Communicational applied CA
- Diagnostic applied CA
- Institutional applied CA
- Interventionist applied CA

Some research streams cover several of these, such as work that began as diagnostic CA which has moved into interventionist applied CA. In recent years, there has been significant progress in using CA as a diagnostic tool, particularly in dementia and seizure clinics. Reuber, a neurologist and conversation analyst, demonstrated that differences in conversational profiles of patients (i.e., the way in with patients talk about their problem) could be used to differentiate between patients presenting with epileptic seizures and those presenting with non-epileptic seizures (Reuber et al. 2009). Since then, diagnostic linguistic features in patient talk have been researched (Ekberg and Reuber 2016; Jones et al. 2016), taught (Jenkins et al. 2015; Jenkins and Reuber 2014), and developed as a diagnostic tool (Mirheidari et al. 2017) in relation to both seizure presentations and dementia.

In interventionist CA, there have been developments relevant to health. Stokoe (2011) has developed a more formal approach to using CA for training in Conversation Analytic Roleplay Method (CARM). Video-taped consultations have been used in medical school training since the early 1980s (Gill and Roberts 2012); however, CARM provides a more structured approach. This involves identifying “trainables” through CA that are then presented in a workshop format along with training on how conversation works. The workshops are created for specific professional groups or workplaces, ensuring that the trainables identified are relevant to the work of the participants.

Robinson and Heritage (2014) describe an approach to study design that factors in the possibility of quantification from the beginning. In this approach, CA is used in

both the preintervention phase to identify the phenomenon to be used in the intervention and in the intervention phase as a way of evaluation and in dissemination. This is particularly useful for interventional research, such as in Heritage et al. (2007). If you are using an interventional approach, designing it as such from the beginning is important.

6 Conclusion and Future Directions

There are many avenues available for future CA in health care including researching different aspects of health care interactions across a range of professions as well as interventional and diagnostic applications, such as those described above. Gill and Roberts (2012, p. 589) argue that “recognition is growing that CA is a crucial resource for medical educators, practitioners and others whose aim is to improve the quality of medical care and relationships among participants in medical encounters.”

The considerable contribution of CA can already be evidenced in its use within clinical communication training, including the leading text on communicating with patients (Silverman et al. 2013). As health care communication training relies heavily on simulation, there is significant scope not only for more CA-based training such as CARM for group training and remediation, but also for critiquing and improving simulation through a better understanding of its authenticity (White and Casey 2016). The use of CA in assessing communication might also be further explored and tested (Kelly 2009).

Looking at the changing nature of health care might lead some to explore less researched areas such as the integration of technology into the interaction, other types of team interaction, or how training and supervision is conducted. This might also include using historical data from larger databases (Jepson et al. 2017) to analyze the way in which consultations have changed over time or to track patients through the health system (e.g., Barton et al. 2016), comparing and contrasting their interactions.

Conversation analysis allows analysts to meticulously analyze conversation in order to understand the architecture of talk. It is increasingly being used to analyze doctor-patient interactions (Heritage and Maynard 2006b). The strength of the methodology lies not only in its use of naturally occurring data, but also in the replayability of the data, allowing it to be viewed and reinterpreted by other analysts. While other methodologies may also use recorded data, the microanalysis of CA develops an intricate understanding of the processes of talk-in-interaction. Although CA is congruent with other observational research methodologies (Clayman and Gill 2004), it goes beyond such observation as it provides analysts with the opportunity to repeatedly observe interactional phenomena. Through CA, we can see how we get things done through talk, that is, what is going *on*, which can help us understand and improve when things go *wrong*.

Appendix: Transcription Notation

The transcription notations that are used in this research are taken from ten Have (1999, pp. 213–214) and Gardner (2001, pp. xi–xxi). These are based on the Jeffersonian transcription system.

<i>Sequencing</i>	
[A single left bracket indicates overlap onset.
]	A single right bracket indicates the point at which an overlap terminates in relation to another utterance.
=	Equal signs, one at the end of one line and one at the beginning of the next, indicate no gap between the two turns. This is called latching.
>	A carat bracket is used within a speaker to indicate no gap between a speaker's turn constructional units.
<i>Intervals</i>	
(0.0)	Numbers in parentheses indicate elapsed time in silence by tenth of seconds. This works within a turn, a turn constructional unit or between speakers. For example, (2.1) is a pause of 2 s and one tenth of a second.
(.)	A dot in parentheses indicates a tiny gap of less than 0.2 s within or between utterances.
<i>Prosodic features of utterances</i>	
word	Underscoring a word or part thereof indicates some form of stress.
::	Colons indicate prolongation of the immediately prior sound. Multiple colons indicate a more prolonged sound.
-	A dash indicates a cutoff.
w-w-word	Stuttering is indicated by a repetition of the stuttered sound connected by hyphens.
*	An asterisk around an utterance or part thereof indicates creaky voice.
\$	A dollar symbol around an utterance or part thereof indicates smiley voice.
.	A period indicates a stopping fall in intonation.
,	A comma indicates a slightly rising, continuing intonation.
?	A question mark indicates a rising intonation.
¿	A "Spanish question" mark indicates stronger rise than a comma but weaker than a question mark.
—	An underline symbol after the word indicates a level pitch contour.
x:x	An underlined colon within a syllable indicates that the intonation within the syllable falls then rises.
xx:	An underlined second letter within a syllable followed by a nonunderlined colon indicates that the intonation within the syllable rises then falls.
	The absence of an utterance-final marker indicates some sort of "indeterminate" contour.
↑	An upward arrow indicates a marked shift into higher pitch in the utterance-part immediately following the arrow.
↓	A downward arrow indicates a marked shift into lower pitch in the utterance-part immediately following the arrow.
WORD	Upper case indicates especially loud sounds relative to the surrounding talk.
·word	Staccato talk is indicated by a bullet prior to the utterance-part.

(continued)

Sequencing

°word°	Utterances or utterance-parts bracketed by degree signs are relatively quieter than the surrounding talk. Very quiet talk is indicated by two degrees signs on each side.
<word>	Left/right carats bracketing an utterance or part thereof indicate slowing down as compared to the surrounding talk.
>word<	Right/left carats bracketing an utterance or part thereof indicate speeding up as compared to the surrounding talk.
.hhh	A dot-prefixed row of “h”s indicates an in breath.
hhh	Without the dot, the “h”s indicate an out breath.
w(h)ord	A parenthesized h, or a row of hs within a word, indicates breathiness, such as can be heard in laughter and crying.

Transcriber's doubts and comments

()	The length of empty parentheses indicates the length of talk that the transcriber was unable to hear. Empty parentheses in the speaker designation column indicate inability to identify a speaker.
(word)	Especially dubious hearings or speaker identifications are indicated by parentheses around the utterance, utterance-part, or speaker designation.
(())	Transcriber descriptions are indicated by double parentheses.

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Unobtrusive Methods

29

Raymond M. Lee

Contents

1	Introduction	492
2	Traces	492
3	Running Records	495
4	Episodic Records	496
5	Observation	497
5.1	Observational Sampling	498
5.2	Hardware Data Capture	499
6	Ethics and Unobtrusive Methods	499
7	Unobtrusive Data Online	500
8	Triangulation	502
9	The Generative Problem	502
10	Conclusion and Future Directions	504
	References	505

Abstract

Unobtrusive methods use ways of collecting data that do *not* involve the direct elicitation of information from research participants. They are useful in situations where it might be dangerous or difficult to question respondents directly or where, for one reason or another, using self-report methods will not yield reliable information. Three main sources of unobtrusive data can be distinguished: traces, documentary records, and direct nonparticipative observation. Each of these is discussed with examples of their use, as is the increasing use of unobtrusive data acquired online. The ethical challenges associated with the use of unobtrusive methods are identified, and the issues involved in their generation are discussed.

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Observation · Online methods · Ethics · Triangulation · Ethics

1 Introduction

There is a recurrent joke in Laurent Binet's (2017) satirical novel *The 7th Function of Language* in which a character on first meeting another person immediately produces a detailed account of that person's biography and way of life based, Sherlock Holmes-like, on observing small details such the presence of a signet ring or the rumpled state of their shirt. The joke would not have been lost on a group of social scientists at Northwestern University in the 1960s who met regularly and made it a game to come up with ever more outlandish research methods. The group – Eugene Webb, Donald T. Campbell, Richard Schwartz, and Lee Sechrest – went on to write a best-selling book, *Unobtrusive Measures* (1966), that set out the results of their deliberations. In the playful spirit that animated their original discussions, they explicitly encouraged researchers to seek out novel, creative, and innovative ways of collecting data rather than reaching automatically for the standard methods then in use, predominantly self-report methods based on questionnaires and interviews, both quantitative and qualitative. The difficulty with such methods, Webb and colleagues argued, was that they were *reactive*. People changed their behavior because they knew they were being studied or tailored their responses to questions in order to create favorable impressions of themselves in the eyes of an interviewer. Unobtrusive methods, by contrast, removed precisely those elements from the situation.

Webb et al. (1966) identify three sources of nonreactive data: traces, documentary records, and observation. Some alternative approaches have been proposed. Emmison et al. (2012) distinguish between two-dimensional visual sources, images, signs, and representations and the like, and three-dimensional sources, such as settings, objects, and traces, and lived and living forms of visual data, i.e., the built environment, human bodies, and interactional forms. Lee (2000) has proposed recasting Webb et al.'s typology to make clearer how particular measures are generated. To this end, traces become “found data,” observational methods yield “captured data,” and documents “retrieved data” (p. 13). Fritsche and Linneweber (2006) make the point that reactivity might be better seen as a continuous rather than a dichotomous variable. They set out a typology in which examples of different methods are distinguished in terms of levels of reactivity, on the one hand, and levels of participant awareness, on the other. Arbitrary though it is, Webb et al.'s distinction is retained here for expository purposes.

2 Traces

As we move through the world, we leave behind traces of our passage. Those traces, “wear, tear and rubbish” (Emmison et al. 2012, p. 132), provide evidence of the actions and processes that produced them. Webb et al. distinguish between two kinds

of trace measure: “erosion measures” produced when a surface is worn away and “accretion measures” produced where material is added to the environment usually by abandonment or adornment. That floor tiles around a popular exhibit at Chicago’s Museum of Science and Industry needed to be replaced more frequently than those around others that were less popular (Webb et al. 1966) has become an almost quintessential, and much cited, example of an erosion measure. Looking at wear on library books can give an indication of how often they have been read (Webb et al. 1966; Abbott 2014), while Emmison et al. note that shiny patches on metal statues provide evidence of the extent to which people have made contact with the statue in some way, by sitting on it, for example (2012).

Litter has creative possibilities. Picasso’s famous sculpture, *Tête de Taureau*, is made from the seat and handlebars of a discarded bicycle. Litter can also be data. New York City banned smoking in parks and on beaches in 2011. Using a before-and-after design, Johns et al. (2013) evaluated the effect of the law by using, among other methods, an audit of litter left on parks and beaches. The ban seems to have produced a significant reduction in smoking litter for beaches and playgrounds but not parks. Interestingly, Johns et al. attribute this pattern to an environmental property of parks; it is harder to clean litter from grassy areas than from areas that are paved.

Webb et al. (1981, p. 21) describe graffiti as the “example par excellence” of accretion data. The presence of graffiti has been used to map territoriality, as in Ley and Cybriwsky’s classic (1974) study of gang distribution in Philadelphia. The content of graffiti can also be a useful measure of attitudes. When a hurricane approaches, people board up windows and doors with plywood, which is then often graffitied. Alderman and Ward (2008) point to how hurricane graffiti allowed residents to express defiance, desperation, concern, or contempt for politicians in the face of an impending disaster. The longevity of certain kinds of graffiti might be significant, as might its absence. Wilson (2014) used the time taken to remove racist graffiti appearing in a small Australian city as a measure of local authorities’ willingness to meet their legal obligations to remove offensive material.

Latrinalia, bathroom graffiti, has been extensively studied. Much interest has focused on how graffiti found in male and female restrooms on university campuses differs in content. Generally, differences seem to be in line with traditional stereotypes, with men being more aggressive and sexually focused and women being more supportive and willing to offer advice. There are signs, though, of a broadening both of context and conceptualization. Trahan (2016) notes the extension of latrinalia studies to contexts such as bars and restaurants and a greater willingness to explore how issues of sexuality intersect with gender (Rodriguez 2016).

Garbage provides an important, if underused, resource for tracking social activities. Founded around 1973 at the University of Arizona by William Rathje, the Garbage Project, as it became known, aimed to apply techniques from archaeology to the study of modern-day waste (Rathje and Cullen 2001). Very much in the spirit of Webb et al.’s work, Rathje and Murphy (2001) point to recurrent findings from Garbage Project studies of a disconnect between self-reports of consumption behavior based on interviews and estimates of derived from studies of discarded packaging. Householders misreported alcohol consumption, amounts and types of food

consumed and discarded, and the frequency with which they disposed of hazardous waste. Comparisons suggest that self-reports were affected by a variety of factors, including difficulties with recall and an apparent desire to portray the respondent in a positive light.

Webb et al. (1966, pp. 43–46) propose that one might improve the reliability of trace measures through “controlled erosion” or “controlled accretion,” that is, manipulating the properties of materials such that erosion or deposit could be more accurately calibrated or situations such that traces are left behind. A carpet might be brushed periodically, for example, to make it easier to see the amount of traffic passing over it. The rate at which leaflets for or against a particular candidate or controversial issue left on car windscreens were discarded when drivers returned to their cars provides a measure of levels of support for the issue or candidate and potentially overcomes biases that can occur when individuals are asked in an interview to express an opinion about a controversial matter (Cialdini 2011).

Although, as Zeisel (1984) points out, thought needs to be given to how trace observations are recorded, obtaining trace data poses few operational challenges. Physical traces can be recorded quickly and at low cost, and relatively large volumes of data can be accumulated in a fairly short time. Data collection requires little cooperation from those within the setting and poses little inconvenience to them. Few ethical difficulties arise in collecting trace data. Personally identifiable material is sometimes encountered in garbage, but in the context of a trace-based study, little reason exists for it to be recorded, retained, or used (Rathje and Cullen 2001). Traces are easy to count and relatively durable. This makes it easy to track them over time or by location, opening up possibilities for longitudinal analysis or between-site comparison.

There are some rather obvious disadvantages to the use of trace data (Lee 2000). Some activities leave no trace or obliterate those already there. As a consequence, the estimates produced are usually conservative. Surfaces can be repaired, disrupting the continuity of data already there. Trace measures are not completely free of response sets or patterns of selectivity in the data. The extent of wear on a surface will depend on its physical properties. Hard surfaces wear less readily than soft ones. A surface, once degraded, wears faster than it did before. Since wear or deposit is rarely a speedy process, accumulating evidence from trace data can take some considerable time. One rarely has population data that would make it possible to calculate a rate for some particular measure.

Traces are “inferentially weak” as Bouchard (1976) puts it. What one can infer from them is limited. Zeisel (1984), writing from the point of view of someone interested in environmental design, for example, argues against the use of the term “accretion measure” precisely on the grounds that Webb et al.’s definition ignores the intention behind the addition of a particular object in an environment. Emmison et al. argue that in the absence of material from more conventional sources or a “strong sociological imagination,” research using unobtrusive methods can produce “banal and largely descriptive inferences” of little interest beyond their immediate context (2012, p. 151).

3 Running Records

For Webb et al. (1966), “running records” are documentary sources produced on a reasonably regular basis in a form broadly comparable from one time period to the next, thus allowing the possibility of longitudinal analysis. By contrast, “episodic records” are archival materials, discrete in themselves and not explicitly time-ordered. Running records are highly diverse; no entirely satisfactory or comprehensive typology or listing exists. They include, for example, official statistics of various kinds: actuarial records; administrative data; government documents emanating from executive, legislative, and judicial sources; and so on. They also encompass a vast range of materials from the mass media, not just news stories but editorials, cartoons, obituaries, advertisements, personal advertisements, wedding announcements, and advice columns.

Uses of running records are as diverse as the records themselves. Tracking the popularity of baby names from birth records allowed Lieberman (2000) to analyze processes associated with cultural innovation. Wiid et al. (2011) explored political sex scandals through an analysis of political cartoons, noting that the eventual outcome tended to depend on who came to be portrayed as the “loser” in the popular imagination. Running records can be used to explore issues difficult to tap using other methods. Using information from local newspaper articles, Rowe et al. (2011) examined incidents where people with dementia went missing. The material allowed them to explore the antecedents of going missing, the characteristics of the people concerned, and the circumstances in which people were subsequently found dead or alive.

“Lonely hearts” advertisements have long been a source for understanding presentations of self and partner selection preferences (see, e.g., Jagger 1998). A fairly extensive literature now exists that examines such issues in relation to age, gender, race, and sexuality. The advice literature has been heavily mined in a number of fields, including the sociology of emotions, despite reservations by historians about how far guidance translates into practice (Lees-Maffei 2003). Many kinds of running record have moved online, making them more accessible. Yampolskaya (2017) has noted that possibilities created by the shift from paper to electronic records have encouraged policy-makers, researchers, and funders to take greater interest in the research uses of administrative data. Typically large, diverse, and comprehensive with low rates of attrition, administrative datasets provide a cost-effective source of nonreactive data on populations in contact with official bodies.

Although they have many advantages, one needs to be vigilant about the constraints, restrictions, and hidden fallibilities that surround running records. Such records are socially situated products; what is recorded is not independent of the processes involved in producing the record. With administrative data, the extent to which material collected is central to the administrative task itself is likely to have a direct effect on the quality of the information collected (Yampolskaya 2017). Trends shown in the data might result from changes in record-keeping practices. Careful judgments, in other words, might need to be made about how measures are expressed, combined, or aggregated.

4 Episodic Records

Episodic records have a more discontinuous form than running records and are “usually not part of the public record” (Webb et al. 1966, p. 88). They encompass, for example, maps, product packaging, architectural drawings, postcards, letters, diaries, suicide notes, regulatory handbooks, records of legislative debates, sales records, institutional records, inscriptions on cemetery markers, and more besides. The range and diversity of such records makes summary difficult (though see Scott 1990). For present purposes, only a few kinds of different types of record will be discussed in detail.

Once a rather devalued genre, “documents of life” (Plummer 1983, 2001) include sources such as life history interviews, letters, diaries, memoirs, and the like that document processes by which individual lives come to be creatively recounted and interpreted. Although perhaps not best thought of as “unobtrusive” in the normal sense of the term, they often have considerable power to illuminate aspects of lived experience not always well captured by more conventional methods. Jones (2000), for example, describes a somewhat unusual instance where an individual who had kept a diary over many years subsequently made it available, unsolicited, to a researcher. A particularly valuable feature of the diary was that it contained contemporaneous accounts of how the diary-keeper had experienced and responded to various medical consultations, including a cancer diagnosis (see also ► Chap. 83, “Solicited Diary Methods”). Documents of life are most readily found in archives and reflect the processes by which archival materials come to be selectively preserved, deposited, and catalogued. Accordingly, they tend to be more readily available for elites or for times past, a circumstance that might limit their applicability for some researchers.

Latterly, researchers have been encouraged to make wider use of data obtained under freedom of information legislation and to broaden the scope of requests beyond the law enforcement and security agencies that have traditionally been the targets of access to information requests (Greenberg 2016). Greenberg argues that research based on freedom of information requests has become easier and more fruitful over time. The processes involved have become routinized; sources are now commonly created in releasable, usually digital, formats; and researchers and officials have a greater awareness and understanding of the possibilities and limitations of relevant legal and operational frameworks. As well as a source of data in its own right, Greenberg (2016) suggests that disclosed material can be used to cross-validate data from other sources and as the basis for case study research on organizations, large bureaucracies. However, it is important to recognize the limitations of such data. Officials can thwart disclosure by self-censoring or by keeping information off the record.

Self-report methods have rather serious limitations in research focusing on wrongdoing, particularly where those involved are relatively powerful. In such cases, researchers can use documents that have come into the public domain through the activities of whistleblowers, the deliberations of investigative commissions or tribunals, or court cases. Public health researchers and others have studied previously secret internal tobacco company documents made public as a result of legal

settlements (see, e.g., Fooks et al. 2011). Emails released following the collapse of the Enron Corporation have been extensively studied by researchers interested in email as a communicative medium (Janetzko 2017), while Lee (2010) was able to use tobacco industry documents dealing with the marketing of cigarettes to trace in part the history of focus group methodology.

5 Observation

Observation might be preferred to interviewing in busy or noisy environments that make speech difficult, where participants are engrossed in their activities or where participants are unwilling or unable to report on their own behavior. What you look like, what you wear, how you move and behave, your speech, your posture, your gestures, how you arrange yourself in space, and how you interact with others can all be seen, recorded, inspected, and analyzed. Aspects of physical appearance – hair, clothing, jewelry, tattoos, and the like – often convey information about culture or status. Meaning is frequently conveyed nonverbally, through gestures or often quite subtle expressions of deference and demeanor. Related to this, people use time, space, and duration to convey social meaning through such things as seating arrangements or the length of time someone is kept waiting for a meeting. Direct observation of such things, “simple observation” as Webb et al. (1966, p. 112) describe it, can often be accomplished easily and in a nonreactive manner. Of course, simplicity can be deceptive. Even straightforward observation is vulnerable to distorting factors. What is to be observed needs to be visible and accessible. It can be affected by the extent to which those studied are unaware or unconcerned about being observed, as well as by observer fatigue, inattention, distraction, or narrowness of focus. What is seen at any given point might not be representative, while the presence or absence of those in the setting might fluctuate in some nonobvious but systematic way.

Sometimes, where behavior occurs infrequently or is relatively indiscernible, the period of observation might need to be prolonged before relevant data emerges. In these circumstances, “contrived observation” is sometimes used. There are by now a number of well-known instances of contrived observation based on the manipulation of activities such as driving behavior, help-seeking, the return of lost objects, and the provision of goods and services. Compared to other unobtrusive methods, contrived observations can be vulnerable to experimenter effects, although they also permit a degree of experimental manipulation of the situation (Fritzsche and Linneweber 2006).

Reiss (1971) has argued for an approach he calls “systematic social observation” that uses explicit procedures for observation and recording designed to ensure that findings are replicable. This approach has affinities with earlier observational studies of children by pioneering female researchers such as Charlotte Bühler, Dorothy Swaine Thomas, and Ruth Arrington, small group research, and the development of observational methods by human ethologists (McCall 1984). However, much of methodological development of systematic social observation took place in the

1970s in the context of research on police-citizen encounters, and such methods, which make use of trained observers, have remained important in criminology (see, e.g., Mastrofski et al. 2010). The overt presence of researchers raises obvious concerns about reactivity, dealt with in this tradition by the observers themselves monitoring in a close and careful way their possible influence on the interaction observed.

5.1 Observational Sampling

Since behavior flows continually through time and space, sampling is necessary in observational research. Martin and Bateson (2007) identify four broad strategies. The observer can record whatever seems relevant (*ad libitum* sampling), though this can encourage a focus on the visible or unusual at the expense of more routine or subtle behavior. In focal sampling, one observes, for a specified period of time, a particular sample “unit” such as an individual or pair of individuals and records all instances of relevant behavior occurring during that time. This can produce a bias toward visible behavior since the focal unit might not always be in sight of the observer. Scan sampling involves sweeping the behavior of a subject or group at regular intervals and recording what is happening at that particular point. It can be difficult to record more than a few categories of behavior when scan sampling, and conspicuous individuals or behaviors can be noticed more readily and, therefore, to be overrepresented. With behavior sampling, a group or setting is observed in its entirety. Each time a particular behavior occurs, its occurrence and the identity of the sample element involved are recorded.

Martin and Bateson identify two methods for recording behavioral data: continuous (or “all occurrences”) recording and time sampling. Continuous recording produces a record of how often and for how long behaviors of interest occur, with start and stop times being recorded. While precise, the observer is often able to attend to only a few categories of behavior limiting the method to some degree. With time sampling, observations are recorded periodically at random intervals, a procedure that in theory is more reliable than continuous sampling since it allows more categories to be measured and more of the subjects present in the setting to be studied. When sampling, behavior measurement accuracy needs to be set against the ease with which measures can be obtained. The former implies short sample intervals, the latter long ones. Choosing an interval will often be a matter of trial and error and/or judgment or need to be determined on the basis of a pilot study.

Two types of time sampling can be distinguished: instantaneous sampling and one-zero sampling. In the former, the observation period is divided up into short sample intervals. At the precise moment each sample point is reached, the behavior of interest is recorded as having occurred or not. Instantaneous sampling does not capture well rare, brief, or inconspicuous events. In one-zero sampling, the observer records at each sample point whether or not the behavior of interest occurred during the preceding sample interval. One-zero

sampling can produce biased results. Behavior is recorded no matter how often it appears or for how long it occurs, and events clustered at particular times tend to be undercounted compared to those that are spaced out evenly across the whole observation period. The method can, though, be useful in studies of intermittent behavior difficult to capture with either continuous recording or instantaneous sampling methods.

5.2 Hardware Data Capture

How to capture and preserve for analysis of what is observed has prompted a recurrent interest in recording and data-logging devices. Manual methods for recording observational data have the virtue of low cost and simplicity. Their relative inflexibility encouraged researchers in many fields to turn toward hardware-based methods that promised accuracy, ease of use, and adaptability. More recently, the advent of handheld tablets and smartphones has opened up a range of newer applications including geo-spatial mapping and data linkage to audio, video, and physiological data (see, e.g., Wessel 2015).

6 Ethics and Unobtrusive Methods

Ethical concerns arise with unobtrusive methods in relation to informed consent, the principle that people should participate in research of their own volition having been fully appraised of what their participation will entail, and with their express agreement having been obtained and documented (see ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). Since nonreactive methods, by definition, avoid direct engagement with research participants, it would seem impossible for that principle to be upheld.

Trace data, documentary research, and some kinds of observational study, such as those taking place in public settings, raise few substantial ethical issues. People in public settings act in the knowledge that their behavior is observable and open to scrutiny. Although visible, they are not directly identifiable. In many situations, sporting events come to mind, gaining permission to observe from those present would in any case be almost impossible. Issues arise most clearly in studies using contrived observation, where the researcher changes the setting to invoke a response or to make some pattern of behavior more visible or where concealed hardware is used to record people’s activity. The former involves deception, while photographs, video, audio, and, latterly, geo-locational data potentially invade people’s privacy and can allow individuals to be identified.

While the responsibility for ethical conduct lies firmly with the researcher, many countries require researchers to have prior approval for their research from an ethics committee or review board. Research using unobtrusive methods might need to be very carefully framed in submissions for ethical approval, balancing in particular wider societal benefits from the research against possible harm to participants and

suggesting, where possible, remedial strategies such as obtaining consent after the event (King et al. 2013). A wider and controversial issue that arises in this context concerns how far, as Page (2000) argues, the principle of informed consent has become entrenched within regulatory frameworks to the extent that it is now difficult to study socially relevant topics such as stigmatization or discrimination using methods that rely on offering people disguised opportunities to act in stigmatizing or discriminatory ways without apparent sanction. How far certain kinds of study have been “chilled” in the manner Page suggests is difficult to assess. A decline in the number of observational studies reported in journals in a number of fields has been attributed in part to the impact of ethical regulation (see, e.g., Giuliani and Scopelliti 2009), although the role of other factors, changing theoretical trends, for example, cannot be ruled out. Focusing specifically on research using visual methods, Wiles et al. (2012) argue that, while concerns about ethical regulation are widespread among social researchers in the UK, it is difficult to find evidence that the system has deterred researchers from using particular methods. They do conclude, however, that “subtle but significant self-censorship” has been one outcome of ethical governance. A number of researchers who participated in their study reported, for example, being increasingly cautious in relation to issues such as the anonymization of visual materials, the ownership of data, and the dissemination practices as a result of ethical committee concerns.

7 Unobtrusive Data Online

Online methods are transforming social research, including unobtrusive methods. It is difficult to arrive at a satisfactory classification of online data sources, but some different types can be distinguished. Increasingly available in online repositories and archive are large volumes of what might be called “retrievables” – episodic and running records such as official documents, historical records, secondary data, statistical material, and so on. These can be distinguished from online materials directly harvested from sources such as webpages, blogs, online forums, and the like. Beyond this are the digital traces that computer systems produce to document their own operations and that are captured in log files (Janetzko 2017). Finally, one can mention “paradata” (Couper 1998), the auxiliary data generated as people complete surveys online, the time taken to answer a question, for example, which provide, among other things, a source of unobtrusive information about data quality and survey operation.

Online user-generated material is not necessarily free of self-presentational elements, but blogs, websites, forums, and online discussion groups have been widely used as sources of unobtrusive data (see ► Chap. 77, “Blogs in Social Research”). Seale et al. (2010) have made interesting use of data from online forums for cancer sufferers. They were able to compare forum data with detailed qualitative interviews from a sample of cancer sufferers. They note that while the interviews were rich in biographical and contextual data, they were shaped by respondents’ self-

presentational concerns and largely retrospective. The large volumes of material extracted from online forums provided, by contrast, direct and contemporaneous information about people's experiences of illness and treatment, and there was more openness about sensitive matters. Clearly, this is not to suggest the superiority of one data source over the other but to point to their complementarity.

Social media data has become a focus of interest in recent years, often under the rubric of "big data," and provides many examples of topics that can be studied unobtrusively. Some topics – fads, fashions, rumors, and protests are examples – are interesting, precisely because their evanescence, fluidity, and impermanence make them difficult to study by conventional means but accessible to online study. Zubiaga et al. (2016), for example, used Twitter data relating to a variety of news events in order to examine how people spread, supported, or denied rumors associated with an event.

The size and complexity of "big" datasets mean they need to be analyzed using computational techniques such as data mining, and there are technical issues associated with their acquisition. Bright (2017) provides an introduction to methods for accessing social media data, including the use of APIs (application programming interfaces), programmatic methods for extracting data generated by a particular provider. The use of APIs can be problematic. They are provided by the social media platform itself, and their use is governed by the provider's commercial interests rather than the needs of researchers. This means what is available through the API can be limited or might change in unanticipated ways that cut off certain avenues of inquiry or make longitudinal analysis difficult. In addition, as Bright points out, the technical aspects of the procedures involved have implications for the skilling of social researchers and the future content of research training yet to be resolved.

Although the accessibility of archival and similar materials has been enhanced by their move online, difficulties remain. While online material can generally be searched easily, keyword searching can make finding nonobvious materials more difficult, while for some sources, the variable quality of optical character recognition used in the digitization process can create problems (Abbott 2014). Online research raises ethical issues. Research conducted online often extends beyond national boundaries raising concerns about ethical governance. In some instances, on online forums, for example, the boundary between public and private is not always clear. Particularly in relation to social media, large volumes of data, techniques for combining datasets, and individuals with fairly unique combinations of attributes mean that anonymity can be compromised. One consequence can be a degree of suspicion that encourages users to be careful about self-disclosure or to provide wrong or misleading information (Janetzko 2017). On the other hand, as Buchanan (2016) points out, the possibility of data breach can make problematic the obtaining of informed consent since users are typically not well informed about policies and practices governing reuse of their data, which, in any case, are subject to change. Issues of informed consent also arise in self-report studies where paradata are collected (Couper and Singer 2013).

8 Triangulation

Webb et al. (1966) were critical not only of reactive methods. The problem with traditional methods was “that they are used alone” (p. 1). Drawing on Donald Campbell’s work on “convergent” and “divergent” validity (Campbell and Fiske 1959), and the use of “triangulation” as a methodological strategy, Webb et al. argued that greater faith could be placed in a study’s results when they had been obtained using different methods. As they put it, “if a proposition can survive the onslaught of a series of imperfect measures, with all their irrelevant error, confidence should be placed in it” (1966, p. 3). Denzin (1970) drew on and extended Webb et al.’s notion of triangulation to refer more generally to the combining of quantitative and qualitative methods in a single study. Subsequently, the issue became controversial. Disputes raged about how far differing epistemological assumptions rendered different methods incompatible rather than complementary (Bryman 2006). Over time, a somewhat broader view gained traction. This saw triangulation in terms of the implicative juxtaposition of different methods understood reflexively in relation to their respective epistemological foundations (Fielding 2010). In all of this, the potential contribution of unobtrusive methods to mixed methods studies was somewhat lost. Also lost, arguably, was Webb et al.’s insistence that researchers would do well to foster methodological imagination, creativity, and ingenuity. Recently, however, many health social science researchers have attempted to employ more creative and innovative methods when working with marginalized and vulnerable people (see chapters under the ► [Chap. 61, “Innovative Research Methods in Health Social Sciences: An Introduction”](#) section).

9 The Generative Problem

Serendipity obviously has an important role to play in the generation of unobtrusive measures. The classic example of wear on floor tiles as a measure of the popularity of a museum exhibit is a case in point. Sometimes, variables or research settings are sufficiently well-tailored to a particular problem that their use commends itself. For example, Lieberman’s (2000) use of data on children’s names to explore processes associated with cultural innovation allows innovations in the realm of culture to be studied independent of organizational or institutional influence, while the organizational processes that surround the registration of baby names are likely to have little effect on the naming process itself, providing data relatively free of artifact. Borrowing a method or technique from somewhere else can also be useful (Abbott 2004). Garbage studies can be seen, for example, as involving the adaptation of archaeological techniques to the study of contemporary consumer culture. What is relatively lacking in the unobtrusive methods literature is systematic guidance to help researchers identify specific methods, approaches, or data sources relevant to a particular research problem.

Although Webb et al. (1966) emphasized creativity, it is not clear that this can be summoned at will. Webb et al.'s (1981) later attempt to develop a "generative taxonomy" of unobtrusive measures proved unwieldy. Subsequently, Lee (2000, Chapter 1) suggested an alternative approach, never fully developed, in which Webb et al.'s typology of data *sources* – traces, running records, episodic records, and observation – is recast as the search for heuristics associated with *modes of data acquisition*, "finding," "capturing," and "retrieving" (on heuristics in the social sciences, see Abbott 2004).

One heuristic designed to capture aspects of routine, mundane, or fleeting aspects of social life or personal conduct is to look for ways of making a setting or situation perceptually, normatively, or culturally problematic. Researchers have used a wide range of strategies to draw out hidden or less obvious features of social situations. Some involve shifting the capabilities of normal human perception. Changing the time base for observation or the depth of focus through which some setting or activity is viewed is one example. Contriving, provoking, and disrupting tactics have commonly been used: the use of props such as lost letters or "breaching experiments" (Garfinkel 1967) in which some norm is deliberately violated in order to see it more clearly is a further example.

A heuristic useful to the identification of physical traces might be to consider how the physical properties of objects are inadvertently implicated in their social use. Webb et al. (1966) tend to see this implicitly in quasi-economic terms. Traces are evidence of production, consumption, demand, and supply. The extent to which production is implicated in consumption triggers their interest in garbage, litter, and so on. Conversely, one can consider what consumption is implicated in production. In practice, Webb et al. (1966) frame this as a question about how demand is naturally calibrated, leading them to consider measures such as abrasion on surfaces. A further and somewhat different heuristic considers the performative opportunities that objects offer directing one to consider graffiti, inscriptions, and the like.

Although it forms only a very brief part of their discussion and they had reservations about using such materials, Glaser and Strauss (1967, pp. 167–8) enjoined researchers to be alive to the potential for using "caches" of documents (see also Ralph et al. 2014). Treating such caches metaphorically as repositories of voices waiting to be heard suggested to Glaser and Strauss parallels between library and archival work and the processes of locating and assessing the usefulness of informants and respondents in field research. With this in mind, asking "How far are there documents to be found that might be treated as if they were informants or respondents sought out on the basis of their developing theoretical relevance to the topic in hand" might form a useful heuristic for identifying and evaluating running and episodic records and other documentary sources. Beyond this, the processes involved in identifying, locating, and retrieving documents often have quite specific heuristics associated with them to do, for example, with useful places to look for material, when to lightly scan materials as opposed to intensively mining them, when to start or stop searching, and so on (a detailed account can be found in Abbott 2014).

10 Conclusion and Future Directions

Webb et al.'s (1966, p. 34) commitment to what they themselves described as "oddball measures" could be seen as a gentle satire on then dominant approaches which unthinkingly applied standard methodological solutions to research problems and treated interviews and questionnaires as methods of choice without regard to their weaknesses. Alvesson and Sandberg (2013) have argued that today increasing specialization often encourages a style of "boxed-in" research that is narrow, fragmented, rigid, and defensive. They propose instead a broad range of strategies for encouraging "box-breaking" research. In this context, Webb et al.'s insistence on thinking against the grain of the conventional has a continued resonance.

It would be an exaggeration to say that unobtrusive methods have needed periodically to be rediscovered in the social sciences, but psychologists at least have on occasion needed to be reminded of their usefulness (see, e.g., Reis and Gosling 2010). In fields such as sociology, measurement-based approaches to unobtrusive data were decisively challenged by the cultural turn emerging in the 1970s that treated traces, documents, and the visual as topics in their own right subject to interpretive and critical interrogation and understanding. Nevertheless, the Australian researcher Michael Emmison (2010, p. 243) has pointed to "obvious methodological affinities" between newer approaches to the visual and to material culture and "an older and these days some – what neglected and unfashionable – branch of social research, the use of unobtrusive or non-reactive measures." Like Webb et al., these newer approaches took "a rather sideways glance at traditional sources of data in social research" (Lee 2000, p. 7) by opening up to serious study aspects of social life often regarded as peripheral, insignificant, or taken-for-granted. They also drew on work in the humanities where elicited data was little used but where sources historically deprecated or marginalized within mainstream social science were important. One might also argue, without overstating the case, that a playful and irreverent stance toward potential sources of data resonates to a degree with certain kinds of postmodern sensibility.

It is possible to exaggerate the case against self-report methods. If you want to know what somebody thinks, it is probably good to ask them. An argument can be made, however, that interviews too often become the conventional rather than the appropriate methodological choice (Alvesson 2003). In difficult or dangerous situations, interviewing is not always appropriate (Lee 1995). Not everything can be verbalized. The recall of past behavior and discussions of sensitive matters is problematic in the interview, which in any case tends to be time and place-bound. To the extent that they do encourage playful and creative approaches, unobtrusive methods force researchers to think beyond methods that are familiar or routine. Simplicity and accessibility are also advantages of unobtrusive measures; they rarely require great technical or technological sophistication and are widely adaptable to many kinds of research situation.

As the twenty-first century progresses, the methodological repertoire is likely to look quite different than it does today. New sources of data will come on-stream, new skills will be necessary, and new technological affordances will likely make it

easier to combine data from diverse sources (Fielding 2014). Such trends are likely to enhance the importance of unobtrusive data, even if some of the forms that data will take are not yet apparent to us. Whatever happens, however, the oblique, the playful, and the creative are still likely to be important. Imagination is no bad thing.

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Autoethnography

30

Anne Bunde-Birouste, Fiona Byrne, and Lynn Kemp

Contents

1	Introduction	510
2	Placing Autoethnography	511
2.1	Automethodologies	511
2.2	Autoethnography	513
3	Doing Autoethnography	516
3.1	Design Questions	516
3.2	Data Gathering	518
3.3	Data Analysis	519
4	Introduction to Case Study Vignettes	520
4.1	Design Questions	520
4.2	Data Analysis and Representation	521
5	Conclusion and Future Directions	525
	References	525

Abstract

Autoethnography is a branch of ethnography that enables a practitioner to also be a researcher and vice versa. While ethnography is concerned with the descriptive documentation of the sociocultural relationships within a given research environment, the researcher remains an observer of the situation under study. Autoethnography enables the researcher to maximize her (his) personal involvement with the action. The researcher's lived experience is an integral part of the

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learning; her engagement with the context, stakeholders, and processes, along with her reflections on that engagement, is paramount to the autoethnographic methodology. Autoethnography is considered to have two clear branches: emotive and analytic. Emotive autoethnography seeks to bring the readers to an empathetic understanding of the writer's experience. Analytic autoethnography allows for the researcher's engagement in the situation to be included in the analysis, adding to the theoretical understanding of the social processes under study by making more interpretive use of available data. Analytic autoethnography is, therefore, particularly useful for the design phases of community-based action research in areas such as community development, health promotion, and social work. This chapter will provide an overview of methods involved in autoethnography, with focus on analytic autoethnography as an "action-oriented" method for social science researchers. Advantages and limitations will be discussed and illustrated with lived experience from the authors' study of complex community interventions.

Keywords

Autoethnography · Health promotion · Translational research · Analytic reflexivity · Crystallization, practice-based research, program design

1 Introduction

I don't want to just be watching, I want to be doing. . .
(Bunde-Birouste 2013, p. 13)

This quote exemplifies the frustration that many practitioner-oriented public health/health promotion/community development-oriented professionals may feel when they are faced with the need to engage in researching their interventions. It may also represent the feelings that practitioner-turned-researchers may feel as they try to grapple with finding a research approach which suits them. This is actually a direct quote from Anne Bunde-Birouste's own doctoral thesis, reflecting her circumstances of being pushed in order to keep her job at the university where she was teaching and managing an exciting research program on rebuilding health systems in post-conflict settings (Bunde-Birouste 2013).

In seeking to positively integrate these demands, Anne, supported by her mentor Lynn Kemp, came to find out about autoethnography, which is the subject of this chapter. Autoethnography is a research method that enables a practitioner to be the researcher and vice versa – the researcher to engage in the doing. The discovery of autoethnography was exciting for both Anne and Lynn; they had grappled with what they found to be extremely complex world of phenomenology, hermeneutics, narrative inquiry, and were extremely frustrated that to research what we wanted to, according to those methods, we needed to distance ourselves. Even ethnography was only about observing – Anne wanted to be doing!

Autoethnography is especially useful for those professionals who are not used to, or are uncomfortable with, research because they cannot see themselves having

to distance themselves from the action – and wondering why their engagement is not “allowed.” Rather than [merely] accompanying the processes involved in the research, the autoethnographer engages actively in both research and program/intervention. This is not to imply that autoethnography does not involve methods, protocols, and rigor. As we will show across the following pages, autoethnography is not just about the researcher, and there are specific methodological parameters to be respected and applied.

The world of research has greatly evolved since the days when only quantitative research was judged to have merit within the positivist tradition. As noted by Wall (2006, p. 147), “the postmodern era has made it possible for critical theories to emerge and take hold in academic inquiry and to open up the possible range of research strategies by the rise of a variety of qualitative methods.” It is not the purpose of this chapter to debate the place of autoethnography within what Denzin and Lincoln (1994) refer to as the fifth moment of research (Denzin and Lincoln 1994; Duncan 2004). This chapter will provide an overview of methods involved in autoethnography, with a focus on analytic autoethnography as an “action-oriented” method for social science researchers. In this chapter, we will set the scene as to what autoethnography is, clarify what it is not, and propose where it is most useful. Advantages and limitations will be discussed and illustrated with lived experience from the authors’ study of complex community interventions.

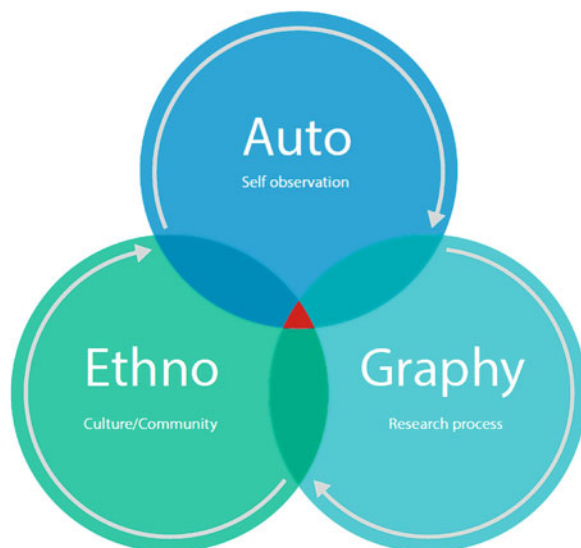
2 Placing Autoethnography

The theory and methods of ethnography has been described in **critical ethnography** and **ethnographic method**, but to briefly reiterate, ethnography is the systematic exploration of people and cultures where the researcher situates him/herself within the community under study. The goal is “to learn from the people (the insiders) what counts as cultural knowledge (insider meanings)” (Green et al. 2012, p. 309). Ethnographic research enables a detailed, often termed “thick,” in-depth description of the culture under study (Liamputtong 2010). Ethnography incorporates “graphy” which refers to the duality of both the research processes and the written representation of that process: that is, it comprises processes beyond “ology” referring to a branch of knowledge. In ethnographic research, however, even though the researchers situate him/herself within the community under study, the researcher is still an observer; she/he may be “inside” the community but not really an insider (for a useful discussion of insider and outsider positions in research, see Corbin Dwyer and Buckle 2009).

2.1 Automethodologies

“Auto”- methods are those that go beyond situating the researcher as an “insider” (Corbin Dwyer and Buckle 2009), that is, “when researchers conduct research with populations of which they are also members” (Corbin Dwyer and Buckle 2009, p. 58; see also Kanuha 2000; Asselin 2003), to the inclusion of, and indeed focus on

Fig. 1 Methodological components



the researcher's first-person experiences of both the object (culture/practice/process) of interest and the process of knowledge discovery and creation (Pensoneau-Conway and Toyosaki 2011). Automethodologies are formed by the intersection of three components: “auto,” the self; “graphy,” the research process; and the epistemological frame, for example, “ethno,” knowledge of culture, community, and social worlds (see Fig. 1).

There are a number of emerging automethodologies, reflecting the combination of insider researcher positioning and the epistemological position of the research/researcher. Figure 2 provides three examples of automethodologies to highlight key components and, critically, to help distinguish autoethnography, the subject of this chapter, from other automethodological forms: autobiography (self [auto], writing [graphy] about their life[bio]), autophenomenography (self [auto], writing [graphy] about experiences or processes [phenomenon]), and autoethnography ([self], writing [graphy] about a cultural or social world [ethno]). Pensoneau-Conway and Toyosaki (2011) provide useful examples of other forms of automethods.

Our focus here is on research defined by Creswell (2008, p. 3) as “research is a process of steps used to collect and analyze information to increase our understanding of a topic or issue,” with steps being drawn from posing questions, making arguments, gathering empirical evidence, and answering the question through empirical claims derived from the evidence. We hence exclude autobiography as a genre of popular literature, as an account of life, usually presenting anecdotal evidence, which does not seek to answer a question or make an argument. Autobiography can, however, provide a data source for research in what can be termed autobiographical research (Coffey 2004). This form of autobiographical research differs from our purpose here, which is first-person insider research.

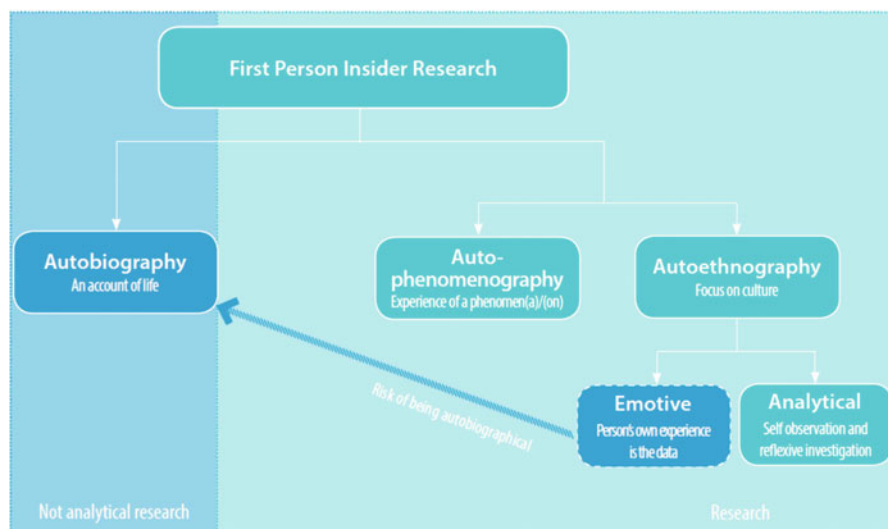


Fig. 2 Automethodologies

Autophenomenography “is about recording what is actually said or happens in a given situation without direct manipulation” (Hasselgren and Beach 1997, p. 197), through self-observation of naturally occurring routine interactions where the author is both the researcher and participant (Allen-Collinson 2011). The researcher engages in both the first-order experience of the phenomenon and the second-order reflection on the nature of that experience (Hasselgren and Beach 1997). The researcher then describes the ways that the phenomenon is experienced (Linder and Marshall 2003; Cibangu and Hepworth 2016).

2.2 Autoethnography

Autoethnography situates itself within the overarching field of ethnography, and in early development, the term referred to the study of a group to which the reflexive observer belongs (Maréchal 2010). The term evolved, however, with scholar Vryan (2006, p. 47) describing autoethnography as “a way to conduct traditional ethnography with a significantly enhanced role for the researcher: the researcher is visible, a ‘strong member.’” Autoethnography, as a method of data collection and analysis, extends beyond (just) the narrative as it seeks to abstract and explain. In other words, autoethnographers should expect to be involved in the construction of meaning and values in the social worlds they investigate. The research is reflexive involving self-observation within a social or cultural world to which they necessarily belong (Pensoneau-Conway and Toyosaki 2011).

Autoethnography has developed a number of “branches” which can essentially be divided into those that seek to be evocative or emotive and analytic autoethnography.

Evocative or emotive branches of autoethnography present ideographic case studies, life stories, or autobiographical performances of first-person narrative aiming to share in an expressive or emotional way the subjective experience of the cultural or social (Maréchal 2010). These methods will primarily or solely draw evidence from the self and reproduce images of the self.

In contrast, the use of analytic autoethnography as a research approach should include systematic methodology in data collection and a diversity in types of data (Ellis et al. 2010). The autoethnographer should include data in forms of interviews, focus groups, and document analysis and could include media analysis if pertinent (see also ► Chaps. 75, “Netnography: Researching Online Populations,” and ► 29, “Unobtrusive Methods”). This moves the analytic autoethnographic approach beyond frequent criticism of evocative or emotive autoethnography (Atkinson 2006) that it is just researchers being “being self-indulgent, narcissistic, introspective, and individualized” (Wall 2006, p. 155). This focus on and analysis clearly positions analytic autoethnography away from autobiography and into research. Analytic autoethnography goes beyond the “me” of the researchers and makes more use of the data. It brings in interpretive analysis. Rather than simply explaining “what is going on,” the analytic autoethnographer seeks to refine and add to the theoretical understanding of the social processes under study (Anderson 2006; Vryan 2006).

Analytic autoethnography is consistent with Ellis’ conception of autoethnography where the researcher’s gaze moves back and forth between an outward focus and looking inward as change agent (Ellis 2004; Ellis and Bochner 2006). It is this view of analytic autoethnography as being disruptive and effecting change that makes analytic autoethnography particularly useful for design, planning, and implementation of community-based public health and health promotion initiatives (Bunde-Birouste 2013).

2.2.1 Analytic Autoethnography

Anderson (2006) designates five features key to analytic autoethnography: complete member researcher, analytic reflexivity, narrative visibility of researcher’s self, dialogue with informants beyond self, and commitment to theoretical analysis. The first attribute of being a complete member researcher means that the researcher has a dual role. She/he is a member of the group under study and a researcher. Acosta et al. (2015) use the term “practitioner-researcher” which represents many professionals in this day and age. The analytic autoethnographer purposefully engages in the action as well as systematically studying it, through observation and documentation, interviews, focus groups, and other data gathering. It is important as well to emphasize that the autoethnographer also engages in analysis and ensures that there is rigorous analysis. Anderson (2006) proposes that there are two types of complete member researchers: they are either “opportunistic” or “convert.”

Opportunistic complete member researchers are either born into the group they are studying, are there by chance circumstances (e.g., through illness), or have acquired intimate familiarity with the group through occupation or some kind of lifestyle participation. Convert complete member researchers begin their belonging through a purely research-oriented situation but become “converted” due

to the complete immersion and membership of the group during the research (Anderson 2006).

Although the autoethnographic methodology involves being a complete member of the group, the researcher has the additional role of being the social science researcher – thus belonging to another group as well. Anderson (2006) cautions as to the tensions that this can pose for the researcher, to be able to manage the documentation, observation, and analysis while at the same time being a member of the group. This multiple focus can evoke tension within the researcher – as the researcher must manage the multitasking. This phenomenon is further represented in the second characteristic of analytic autoethnography – analytic reflexivity. Atkinson et al. (2003, p. 62) contend that “autoethnographic data is situated within the personal experience and sense making of the researcher; s/he is part of the research process, an integral part of the story as it unfolds and that s/he shares.” As an active participant, rather than a passive observer, the autoethnographer then should expect to be involved in decision-making and potentially engage in divisive issues (Anderson 2006). This again may take time for the researcher to come to terms with feeling initially that they can actively engage in decisions.

The third defining characteristic of analytic autoethnography, according to Anderson (2006), is what he calls the “narrative visibility of researcher’s self”: the researcher must not only be visible, active, and reflexively engaged during the research but must be highly visible within the text. As authors, analytic autoethnographers frame their accounts with personal reflexive views, situating their data within their personal experiences and sensemaking (Bunde-Birouste 2013). Here, again the autoethnographer is different from the others engaged in the processes, be they design development, planning, or implementation. The autoethnographer’s engagement goes far beyond the experience of the moment because she/he is more fully engaged in the experience through the analysis, which involves also including their own lived experience in the data and analysis of it as integral to the whole. Further than engagement is the “textualizing” of this particular place of the researcher. The challenge for the autoethnographer in relation to this third characteristic is to include the self-reflexivity, and recount it, but without becoming the only focus of the study, which scholars in the field refer to as “self-absorption.”

To avoid this latter pitfall, the fourth feature Anderson shares in analytic autoethnography involves “dialogue with informants beyond self” (Bunde-Birouste 2013). This crucial element involves a conscious commitment to engage with others along the journey. This feature significantly differs from traditional ethnography. Conscientious engagement with the experience as captured through the different data is needed to reach beyond the sole experience of the researcher to “make sense of the complex social worlds of which we are only a part” (Atkinson et al. 2003).

Just as the first four elements are logically linked and build upon each other, the fifth feature of autoethnographic study involves “commitment to theoretical analysis” (Anderson 2006). This is one of analytic autoethnography’s distinguishing characteristics. The autoethnographer needs to refine, to add theoretical understanding to the use of empirical data, to gain insight beyond that of simple narrative description.

3 Doing Autoethnography

3.1 Design Questions

We would suggest that the first step to using an autoethnographic approach would not be dissimilar to many other research projects, which is taking time to figure out what you want to do and why and, particularly in the case of automethods, by whom and, subsequently, how best to do it. Critical to keep in mind is the integration of purposeful and deep reflexivity across all phases of action and research. This reflexivity is perhaps the most distinguishing characteristic of autoethnography and sets it apart from other research methods (Duncan 2004; Wall 2006; Acosta et al. 2015).

The following graphic presents some critical domains of design questions for autoethnography, which are described further below (see Fig. 3). Section 4 provides a case study that details how these design decisions determined and impacted on an autoethnographic study by Anne Bunde-Birouste (ABB) of the development of a complex community health promotion program.

3.1.1 The Context (Setting)

The importance of context, always significant in any research endeavor, has specific meaning with regard to autoethnography. In an autoethnographic study, context is not only referring to the physical setting and cultural context in which the study is implemented, but importantly it concerns how the researcher came to be there, the how, the why (Anderson 2006; Vryan 2006). As discussed earlier in this chapter, what the setting means to the researcher, how it influences them, the history that the researcher(s) brings to it: their past experiences, their disciplinary back grounds, world views, and personal experiences, all contribute to the richness of the learning. Logically the same context is relevant for members of a collective autoethnographic study (see case study example Sect. 4.1.1).

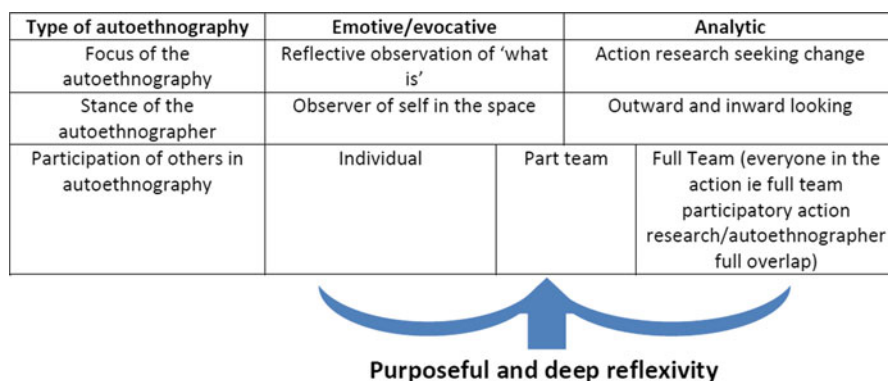


Fig. 3 Design domains

3.1.2 The Why

The focus, or purpose, of the study needs to be clear to the autoethnographer: Is the study being done to observe what “is” (usually associated with evocative/emotive autoethnography) or to catalyze or accompany action, hence to affect change? Moving along the design continuum, the engagement of the autoethnographer can go from being a “self-observer,” focusing on what is happening to him/her but not driving any change, to engaging to drive some of the action, being progressively more involved in what is happening to others as well as self, to fully driving the action (see case study example Sect. 4.1.2). Autoethnography is increasingly being considered a practical and pragmatic approach to take in combination with various action research approaches, including the diverse forms of participatory action research (Acosta et al. 2015).

For instance, is this research the foundation for program design? Or, is the objective of the research to accompany and assess program implementation and impact, hence designed to accompany an intervention in an action research framework? Is the research retrospective; is the study being done to observe and document an initiative, and if so for what purposes? The aims and objectives of the research will influence how the autoethnography is set up and whether it would be an individual research project, driven and implemented by a single autoethnographer or whether it is a variant of collective autoethnography (see Sect. 3.1.4 below). The answers to these questions will influence where the research or researchers are placing themselves and what data collection and analysis methods are to be used.

3.1.3 The What

The autoethnographer’s stance determines, and is determined by, the object of the research, the what: Is the self the sole object or the self and others? In the former, as per emotive/evocative autoethnography, the self is the object. In the latter, the autoethnographer is both outward and inward looking, noting that an autoethnographer cannot be only outward looking as self-observation underpinned by reflexivity is a distinguishing characteristic.

When conducting action-focused autoethnography, taking an outward and inward looking stance, and regardless of whether autoethnographic research is used in a design phase, planning or implementation of a program or intervention, intentional planning of the phases of research elements, and linking to planning of the program/action components are essential. Ideally, the same care in planning the different phases of action will be accompanied by similar care in planning the steps to the research, which will be carried out in parallel. It is important to set out the autoethnographic stance before beginning the action, in all phases from prepping the research, to analyses, writing and sharing it. The various phases of action need to be considered, planned, and underpinned by preparatory research. Similarly, the various forms of data and data gathering will need to be considered, arranged, and scheduled; in other words, they need to be based on previous research, sequential, structured, and purposeful (see case study example Sect. 4.1.3).

3.1.4 The Who

One of the attractive characteristics of autoethnography is that it can be done either solo or with a group of stakeholders (Acosta et al. 2015). The choice of this will depend on where the researcher/practitioner is placing him or herself and as such is one of the very first and crucial decisions the researcher should make, as the ensuing research design will depend on it. In such cases, there are multiple scenarios. It is helpful to consider the participation design domain of solo to full group autoethnographic participatory action research along the lines of a continuum (see Fig. 3 above). Some autoethnographic research will be solo; in other words, the autoethnographer, alone, is designing, driving, and analyzing the research him- or herself. In this case, although there may be other actors involved in the initiative, or action that is being researched, the autoethnographer manages the various research stages, data collection, and analysis alone.

In some instances, the autoethnographer drives the research action and analysis yet also integrates and supports a team-based approach, in which the reflexivity is done solely by the autoethnographer, but she/he integrates learning from involvement of stakeholders along the way. This is not to imply that the full community or action team has stance of the autoethnographer; they can be involved, yet the autoethnographer is still the solo researcher. Progressing further along the continuum from solo to group is the scenario where a single researcher drives the research yet engages “collectively and cooperatively within a team of researchers” for the stages of analysis (Chang et al. 2013; Acosta et al. 2015). As such, the group, or team, begins to be involved in the autoethnographic process. Chang et al. (2013) call this “type” of autoethnography as “collaborative autoethnography,” while Acosta et al. (2015) call it collaborative and analytic autoethnography (CAAE) in action research inquiry. This team approach can remain somewhat “driven” by a single autoethnographer in that one person takes ultimate responsibility for moving things forward and final processing of analysis (see case study example Sect. 4.1.3). Finally, at the far end of the spectrum is the full group autoethnographic process, wherein all members are fully autoethnographically engaged in all stages of the research.

In the following sections, we will focus on analytic autoethnography that is focused on change and both outward and inward looking, which may be conducted by an individual autoethnographer or engage a team.

3.2 Data Gathering

As noted earlier, use of analytic autoethnography as a research approach should include a systematic methodology in data collection and a diversity in types of data (Ellis et al. 2010). The data sources will be in different forms, mixing query, reflections, observations, and straight noting of activity. There will be the personal involvement of the researcher-practitioner and “classic” elements of ethnography such as participant observation and specific and significant diarizing of activities (see ► Chap. 26, “Ethnographic Method”). In addition to these researcher-/practitioner-

specific elements, there are the additional data gathering mechanisms to include: interviews, focus groups, and document/media analysis. We suggest that communication elements such as meeting minutes and e-mails can also be brought into the data pool. These bring in information additional to autoethnographer's notes and contribute to corroborating findings or ensuring trustworthiness of the data.

From this collective, compiled analysis, the full story emerges, and with it the contribution to learning unfolds (Bunde-Birouste 2013). In examining results from different methods of data gathering, the metaphor of triangulation is the common term currently used to corroborate findings and ensure trustworthiness of the data gathering methods (Denzin and Lincoln 1994). For autoethnographic studies, we prefer a technique that more fully recognizes the variety of facets involved in any given phenomenon – crystallization (Richardson 1994; Wall 2006). Acknowledging that there are “far more than three sides through which to view the world,” the crystallization approach is particularly appropriate for autoethnographic studies where methods used are multiple and thus often complex (Richardson 1994, p. 522). Crystallization, as explained by Richardson (1994), deconstructs the traditional idea of validity without losing structure, providing a deepened and complex understanding of the phenomena. This approach allows for the diverse, sometimes minimally structured, data sources, recognizing that they will all contribute to a better understanding of the whole. Each source of data does not have to be comprehensive in and of itself – but must be comprehensive across data sources (Kemp et al. 2008). The rigor and structure will come in the analysis, as opposed to the sources (Bazeley and Kemp 2012; Bunde-Birouste 2013).

3.3 Data Analysis

As noted in Sect. 2.2.1 analytic autoethnographic research involves multiple layers of analysis to interrogate the data to find the “hidden story” within new learning (Bunde-Birouste 2013). As with any qualitative research, there are multiple and progressive steps to data analysis and discovering the depth of the story that the research is telling. The progressive steps of analysis enable interrogation of the complexity, separating the background noise to delve deeply into the “story,” discovering underlying themes, and exploring the findings to understand their different facets (Bunde-Birouste 2013).

A critical part of autoethnography is the hard thinking about how to “represent” the data. The choice of how, where and why the story is told, will frame the representation of the data and the telling of the story. To enable engagement with the story the data is telling, autoethnographic analysis is often presented in some form of analogy, commonly employing literary or visual metaphors. As the steps in data analysis progress in an iterative fashion, often the choice of representation format comes in early in the process. This is perhaps best understood by reading the excerpts from our case study (see case study example Sect. 4.2).

4 Introduction to Case Study Vignettes

Our case study is from Anne Bunde-Birouste's PhD research, "Kicking goals for social change." This is a story of how a vision turned into a viable social innovation program using football to support refugee youth and families feel welcome in Australia (see www.footballunited.org.au). The study examined the challenges and processes involved in the design and development phases of a program that uses football as a vehicle to contribute to building social inclusion in complex sociocultural settings in urban areas of Western countries, such as Australia, that largely consist of refugees from fragile and conflict-impacted areas. This is also a story of how a practitioner came to reconcile herself with research by using an auto-ethnographic approach. Finally, this is a story that proposes that health promotion consider the change agent through the lens of social innovation as a better fit for the complex world of community-based health promotion. The autoethnographic methodology allows for appreciation of the researcher as a social innovator. Significantly, the tale contributes new learning into responsive program design in what is increasingly referred to as complex, community-based health promotion interventions and presents the value of autoethnography as an effective method for research in health promotion, one currently underappreciated and underused.

4.1 Design Questions

4.1.1 The Context

Anne was working in the area of health and peace building, with particular emphasis on post-conflict health sector redevelopment. Through this work, she became highly sensitized to the dramatic plight of refugees, asylum seekers, and humanitarian immigrants. In a previous life, she had witnessed the power of football (aka soccer) to bring people together:

I was among more than 350,000 people gathered to celebrate the French National Team's World cup victory in 1998. My then little 8 year old son and I were among those hundreds of thousands, and were completely and utterly awestruck not only by the number of fans, but by the indescribable shared euphoria of all of them, and even more so by their diversity. Old and young, rich and poor, black, brown and white, all races and ethnic groups brought together by the amazing victory on the football (soccer) field. Ecstatic people crowding on the Champs-Élysées to celebrate the multi-racial French victory team, at a time when the country was significantly frayed by racial tensions.

During my professional life as an international practitioner in community-based health promotion and community development I also witnessed the passion and popularity that the "World Game" had across the entire globe. There is not a community where one does not see children, youth and adults kicking balls around, playing on makeshift fields, often barefoot.

4.1.2 The Why

These two phenomena, Anne's professional expertise and the popular passion for football (including her own), combined into a vision that she wanted to explore:

Could she find a way to use football to “bring people together” and help newly arrived refugee and humanitarian immigrants settle into Australia? A great idea – a vision. But how to develop this vision into a viable program? Of course, community-based, action research seemed the way to go according to her theoretical background. Yet, she struggled with how to remain outside the action when she felt that the:

vision was so powerful, I could literally see the programs happening. After considerable exploration of methods in the area of action inquiry and reflective practice, and pondering about how best to approach the research, my supervisor suggested that the approach best fit for her was autoethnography, which allowed me to be part of the research process, an integral part of the story as it unfolded and that I would share.

4.1.3 The What and the Who

In setting out to explore if Anne’s vision that the passion that the world game of football could bring people together and help newly arrived feel welcome and belong, Anne traversed several pathways in her autoethnographic journey. Committed to a participatory, responsive approach to her research, Anne followed the classic path of engaging with various stakeholder groups across all phases of her research, initially attempting to work consistently with a core steering committee. As challenges emerged and pilot efforts came and went, it became clear that her role was that of the driver, the change agent, and sole autoethnographer: the main character in her cast of dozens.

As the initiator and driver, I was constantly juggling with the desire to maintain principles of consultation and participatory decision-making versus the need to just get on with the development. I was hesitant to be too directive, feeling that I might undermine the concept of participatory community building. This consultative process was frequently not understood by the community members or even the Steering Committee (SC), who often wondered why I continued querying and discussing, rather than taking the lead in decision-making. I realized that they were not understanding what I was trying to do, which prompted the understanding that at times a pragmatic approach was needed. A driver was needed; I had that role and also needed to be a leader in taking a decision and moving the group forward.

Through these experiences, Anne realized that the fitting design for her study was analytic autoethnography, focused on action research seeking change, led by herself as the individual sole ethnographer but taking and outward and inward looking stance (Fig. 4) (Bunde-Birouste 2013).

4.2 Data Analysis and Representation

The choice of metaphor for this study was that of literary analysis. Literary analysis goes beyond a surface reading of a text, story, or, in this analogy, a theater play. As in the analysis of a play, the setting or context within which the story takes place

Type of autoethnography	Emotive/evocative		Analytic
Focus of the autoethnography	Reflective observation of 'what is'		Action research seeking change
Stance of the autoethnographer	Observer of self in the space		Outward and inward looking
Participation of others in autoethnography	Individual	Part team	Full Team (everyone in the action ie full team participatory action research/autoethnographer full overlap)



Purposeful and deep reflexivity

Fig. 4 Case study example of design domain choices. (Source: Bunde-Birouste 2013)

includes not only time and location but it also includes the multiple levels of social reality present. A play is an evolving story with multiple stages and many acts. A play mirrors life, which is ever changing – as was the experience of Football United’s development. Stories evolve, as does life, and as do health promotion interventions and necessarily the processes to design them. A play may have many actors and, like analytical autoethnography, is not a “one-man show.” The analysis involved needs to go beyond that of the self. Within this construct comes the challenge to reproduce the views of the other actors.

A theater play has a number of different parts that combine to tell the story: the plot, subplots, characters, theme(s), tone, and stage. As within any tale, it can be viewed superficially or examined more deeply. A theater review requires objective analysis beyond the apparent and involves more than a simple plot summary – it must be grounded in the production itself. Anne’s ethnographic study was indeed grounded in the action from initial conception and enabled her to see beyond the superficial – to explore the depth of what is really going on as I moved from a good idea to build a viable program concept.

The initial experience of a play is often summarized by critics in the *plot synopsis*. This is the general impression when you first experience the play: you view the stage, “feel” the overall story, gain an overall impression of the subject matter and genre (in this case community-based health promotion), and see the things you expect to see. Correlating this stage to autoethnographic study, it relates to the initial immersion in reviewing data following the fieldwork.

The initial steps to discover underlying themes and explore the characters to understand their different facets bring in character notes and further plot analysis to unearth the various story lines. To enable her to move beyond the plot synopsis, Anne needed to take a number of progressive steps, as summarized in the following table (Table 1) and detailed further below.

The plots synopsis development provided a good sense of things that a “standard” production might involve. A more profound appraisal of the play was needed to begin to look deeper into the characters, to understand their various facets, and what

Table 1 Theater review and steps for analysis

Theater review	Steps for analysis
Plot synopsis	Coding according to genre: exploration of data with community-based health promotion elements in mind; data entered and coded in free nodes in NVivo
Character notes	Clarke's framework for situational analysis (2003) used to delve deeper into the data to explore beyond the surface; framework elements recorded in tree nodes in NVivo
Plot analysis	Multiple methods to interrogate the data to find the "hidden story" within new learning; interrogating the complexity; separating the background noise

they contribute to a deeper meaning to the experience. This next level of analysis required a review of the initial data analysis with a more in-depth manner of coding; the choice of Clarke's (2003) framework for situational analysis is used for this step.

Clarke's framework analysis was appropriate as it enables a researcher to draw on multiple data sources including, among other things, participant observation, key informant interviews, focus groups, and any other data sources the researcher deems relevant (Clarke 2003). The method allows the researcher to draw together action, structure, context, history, and agency for analysis of complex situations. Clarke's framework was particularly suited to Anne's preliminary level of analysis given that it draws on ecological frameworks to map the key human and nonhuman elements involved in the processes under study. This mapping of connections enables a further and deeper analysis and according to Clarke, enhances the analysis as it allows the social side to be added to the more individualistic analysis, which is the center of ethnographic, narrative, and other forms of interpretive phenomenology, thus providing for a full situation analysis, which is sensitive to the complexities, multiplicities, and contradictions, and taking them seriously. It is a particularly useful method of analysis for complex, community-based autoethnographic research. Again, multiple levels of analysis within this phase enabled me to come up with more significant understanding of the characters and deeper meaning to the forces at play. The resulting character notes were extensive and shed an interesting light on the overall story, yet they only told part of the tale.

To understand further required a plot analysis, which would pull all the various elements of the story together by delving into context, character analysis, and story lines, with the intent to unearth the deeper, hidden story or stories. These subliminal stories may either highlight new learning or perhaps shed new enlightenment on old issues.

Trying to find the "hidden stories" in her production proved to be more of a taxing process than Anne would ever have imagined. She ended up referring to this very long stage of interrogating the data as "drudging through the analysis." She reviewed the framework analysis, reviewed relationships, developed further tables, matrixed learning, and checked for cross-referencing, pulling out issues, querying them, and then doing it all over again and again and again. To be honest, it was exhausting! However, it all did end with an intriguing plot analysis, which produced significant learning as to situation, processes, managing complexities, and future potential.

The resulting learning is presented in the “Reviewers” critique, which brings together the results from the various stages of analysis and, by applying a final “filter,” provides us with what might be commonly referred to as discussion and conclusion in a more traditional presentation of research results. Anne found this a fascinating step, one much more interesting than the fatiguing multiple layers within the previous analysis stages.

One thing that plagues those working in community-based programs and health promotion in general is the complexity; managing this complexity in research, and particularly design phase, research can be overwhelming. The challenge is to work through the complexity; filter out the background, offstage, and audience sounds; and focus on recurring bits to understand how the various elements and forces come together. Complexity scholars Funnell and Rogers (2011) advise to focus on the characteristics that are most relevant in developing a program theory to decipher the complexity.

If we can succeed with an effective filtering mechanism, one might consider that the complex becomes merely complicated; the chaotic feeling of being overwhelmed (feeling unable to act) becomes one of analysis, understanding, and then managing. We need to unpack the complexity and in doing so will often find that we move in a sense back from complex to complicated. Anne’s own attenuation filtering process (see Fig. 5) was the application of the editing framework to the draft sections of the character notes, where she queried each section to explore: What are the forces, what did they do, how did they move the story forward, and what do we conclude from it?

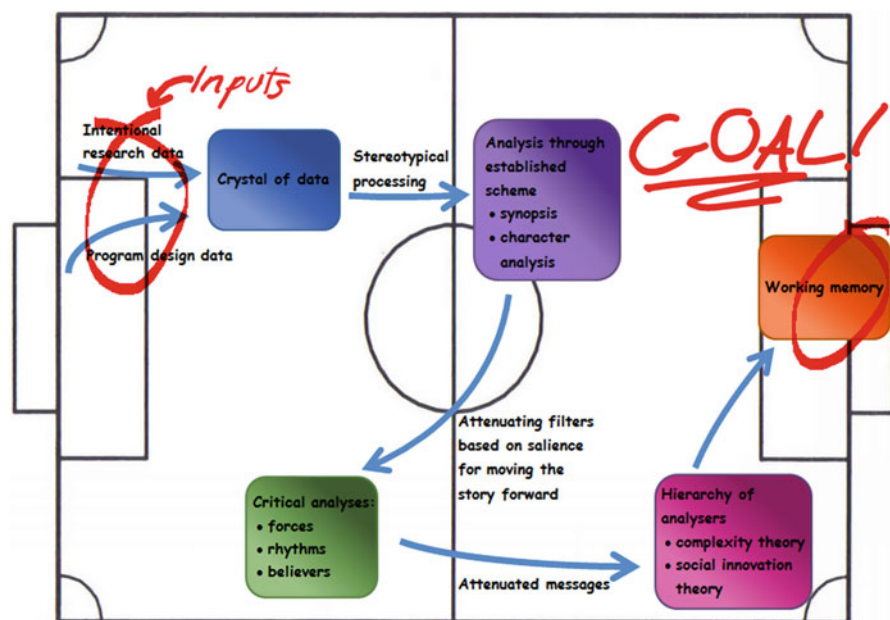


Fig. 5 Taking the inertia out of complexity (ABB attenuation filtering model)

The resulting “story lines” provided the final results in the reviewer’s critique, which in her case were two: the value of analytic autoethnography in health promotion research and particularly the importance of it to underpin the design phases of programs or interventions and that community-based health promotion involves working with a set of complex social innovation processes, which require the practitioner, if she/he is to be effective, to be a social innovator. Because the mechanisms of transforming the vision to action often seem elusive, the social innovator can be particularly aided through an autoethnographic approach. Through analytic autoethnography, the social change processes are underpinned by a robust research technique which enables analysis and processing – allowing us to apply the learning for future social change endeavors.

5 Conclusion and Future Directions

Autoethnography, particularly analytic autoethnography, is an emerging method that supports the practitioner-researcher to be subjectively and fully engaged within the action being studied. We propose that it is especially useful for studying community-based health promotion as a set of complex social innovation processes, where the genesis of the social change is a desire to change the “what is.” The autoethnographic method can have significant implications for health promotion research, in particular, the practice-based research that is increasingly sought from theorists. As we look for more practice-based research to inform policy and theory, an autoethnographic approach is particularly effective. It can empower the practitioner to become the researcher. Autoethnography acknowledges the researcher’s experience and expects that it will inform the research. Yet, it is not just about the researcher, and there are specific methodological parameters (Anderson’s five features; refer to Sect. 2.2.1) in analytic autoethnography that ensure the researcher engages in a high level of dialogue with informants and in commitment to theoretical analysis. As such, this is an excellent method to provide the foundation for future practice-based research.

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Memory Work

31

Lia Bryant and Katerina Bryant

Contents

1	Introduction	528
2	When to Use Memory Work as a Research Approach	530
3	Doing Memory Work	531
4	Memory Work and Social Transformation	536
5	Ethical Considerations	536
6	Conclusion and Future Directions	538
	References	538

Abstract

Memory work is a methodology and method first introduced by Frigga Haug and others in Germany and appeared in academic publications in the 1980s. As an approach to data collection, memory work involves writing a memory in the third person in relation to a question or theme. The methodology and method was used with groups of women to examine power relations through writing and analyzing specific situations. Memory work is an approach that enables emotions to come to the fore, particularly emotions that are not easily voiced. Through processes of writing in the third person and time for analysis and rewriting, the approach provides distance and space for the emotional and sensory to emerge. Memory work facilitates the discovery of the tangible and intangible aspects of sensations that may not emerge from other qualitative methods like semi-structured interviews. In this chapter, the research processes for using memory work are outlined

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and contextualized in relation to working with individual participants and groups. Processes for analyzing memories are explained and examined as are the ethical dimensions of writing, sharing, analyzing, and publishing memories that have arisen from groups or participants.

Keywords

Memory work · Collective analysis · Ethics · Reflexivity · Social transformation · Living historically

1 Introduction

I can only note that the past is beautiful because one never realizes an emotion at the time. It expands later, and thus we don't have complete emotions about the present, only about the past. (Virginia Woolf)

Memory and perceptions of place, people, and events may come into being through a constellation of, or singular, visual images or scenes, language, and/or sensory perceptions and emotions. Understanding how memories work has been the foci of many disciplines over time including history, psychology, and philosophy. As postmodern theories of memory came to the fore, increasingly conceptualizations of memory were understood as fragmented, nonlinear, and not about remembering “how it really happened” (Haug 2008, p. 538). Theorizing memory as temporally created and recreated which is “true” for the individual – that is, telling a story about an event, experience, place, or emotion – dislodges circular debates about memory and its relation to truth.

Memory work is a methodology and method first introduced by Frigga Haug and others in Germany and appeared in academic publications in the 1980s. As an approach to data collection, memory work involves writing a memory in the third person in relation to a question or theme. It can be used in conjunction with other approaches including photography, diary entries, interviews, or focus groups. Initially, memory work was constructed as a tool and theoretical device to examine female sexualization (Haug 1987). Haug and others critiqued psychological and sociological knowledges which prioritized abstract theorizing to understand women's experiences that resulted in “flattening the multiplicity and diversity of experiences” (Stephenson 2005, p. 35). Haug was seeking to develop an approach that would challenge the “opposition between objective, transcendent theory and subjective, bounded experience” thereby “returning to the experience side of the divide” (Stephenson 2005, p. 35). In this way, Haug and colleagues were using a grounded methodology using experience and subjective experience to develop theory. By centralizing the perspective of the subject, Haug and others disturbed the notion of the objective researcher and the participant as the subject of research. In memory work, the researcher becomes both the object and subject of research.

Haug and others (1987) developed memory work as a collective strategy that “was written with and for the feminist movement” (Haug [undated](#), p. 2). The methodology and method was used with groups of women “to provide understandings of relations of power through writing and analyzing specific situations in their recollections” (Bryant and Livholts [2014](#), p. 285). Collectivity in the approach was important as it provided the basis for a discussion of individual experiences in relation to broader social issues. For Haug et al., the purpose of memory work was to move beyond documenting inequality. The memory work project was to provide a process for social transformation. They “wanted to do academic work which had an explicit political value...[and] enabled identification of an intervention...” (Stephenson [2005](#), p. 35).

Although first developed as a collective method (Haug et al. [1987](#); Crawford et al. [1992](#)), over time memory work has also been used as autoethnography (Bryant and Livholts [2013](#)) and with individual participants (Onyx and Small [2001](#); Shea et al. [2016](#)). For example, Widerberg ([1999](#)) used memory work as autoethnography focusing on sexualization of the body. Her analysis of her memories showed how experiences of sexual harassment during her school years shaped her choices and participation in higher education. Shea et al. ([2016](#)) used memory work with individual participants to examine younger women’s identities while negotiating motherhood and transitioning to adulthood. Participants were asked to write a memory on the positive experiences of becoming a younger mother and another on a challenging experience. Shea and colleagues ([2016](#)) found that younger mothers while internalizing discourses about younger mother’s as “dysfunctional” also resisted these, drawing on feelings of pride and resilience. Memory work enabled participants to reflect on their experience of mothering alongside dominant discourses enabling “emotions to come to the fore, with fear and uncertainty being overcome by pride, self-belief and determination” (Shea et al. [2016](#), p. 851).

Henriksson et al. ([2000](#)) and Bryant and Jaworski’s ([2015](#)) work are examples of studies using collective memory work to explore the “everyday” and “personal” emotions and experiences of doctoral students in the academy. Through writing memories, doctoral students identified that thesis writing and the production of knowledge were imbued with emotions of risk, fear, and shame despite hegemonic understandings that privilege rationality and using technical skills to producing theses (Bryant and Jaworski [2015](#)). These studies brought into focus the embodied aspects of study that conflict with the structures, cultures, and process in neoliberal universities when studying for a doctoral qualification.

Memory work, while used collectively with individuals or by a researcher as autoethnography, cannot be simply categorized as a collective and/or individual method (Bryant and Livholts [2007](#)). As a collective method, individual members are writing and also analyzing memories individually and constructing knowledge about themselves and the social world. In this sense, while a collective method, memory work is also an individual method. In research that involves individuals, memories are often analyzed by participant-researchers and academic researchers and as such, also creates collectivity.

In this chapter, the research processes for using memory work are outlined and contextualized in relation to working with individual participants and groups. While the steps are sequential, analysis is ongoing with theorizing and analysis often occurring in tandem. Processes for analyzing memories are explained and examined as are the ethical dimensions of writing, sharing, analyzing, and publishing memories that have arisen from groups or participants.

2 When to Use Memory Work as a Research Approach

Memory work has been used across multiple disciplines including nursing, sociology, psychology, social work, human geography, and gender studies. In health and associated disciplines, it has been used to research a wide range of topics including pain (Gillies et al. 2004), lived experiences of HIV (Stephenson 2005), young people's experience of contraception (Harden and Willig 1998), and gender and caring (Bryant and Livholts 2013; Livholts and Bryant 2013).

Memory work is an approach that enables emotions to come to the fore, particularly emotions that are not easily voiced. Through processes of writing in the third person and time for analysis and rewriting, the approach provides distance and “space for the emotional and sensory to emerge in ways that may not occur or may not be allowed for in for example, a face to face semi-structured interview” (Bryant 2015, p. 11). Simply put, writing memories allows focused attention to detail. Other qualitative methods are less likely to involve descriptions of color, taste, and sound – the surrounding thoughts and images that make memories. Memory work facilitates the discovery of the tangible and intangible aspects of sensations (Mason and Davies 2009). The approach assists in examining the intangible, shifting, and hard to articulate concepts like identity or awareness of one's body. Gillies et al. (2004, pp. 111–112) argued that when using memory work to write about sweating and pain, they generated rich descriptions of their bodies as well as psychological and emotional experiences. Writing memories brought greater attention to experiential aspects of pain. In terms of the tangible, writing memories, according to Jansson et al. (2008, p. 236), allows “focusing on the ‘banal’ and tangible everyday practices, [and] comes across as a very rewarding method to grasp deeply naturalized structures that are difficult to discern in other forms of empirical materials, just because they appear so unimportant and unproblematic.” Moreover, researchers using memory work have argued that writing memories brings forth new unexpected knowledge which is able to be viewed as “social and political. . . [therefore] plac[es] the blame and responsibility beyond [the] individual. . .” (Jansson et al. 2008, p. 238).

As memory work is a method rich in description, it can bring the past more firmly into the present. This brings forth previously unarticulated thoughts or emotional pain. Consequently, memory work as an approach requires skilled facilitation of the group or individual participants, preorganized pathways to access counseling or other services, and enough time for group sessions to provide support to members.

3 Doing Memory Work

Haug's intention was that the stages and process of memory work remain flexible and adaptable, and, therefore, memory work has been adapted in various ways (Stephenson and Kippax 2008). Crawford et al. (1992) suggest the following four steps are useful in creating a theme, writing a memory, undertaking analysis, and interpreting in relation to theory.

1. Identify a theme or question.
2. Write a memory in the third person in as much descriptive detail as possible avoiding biography and interpretive comments.
3. Analyze memories individually and within the group. New questions are proposed, and new memories are written or original memories rewritten.
4. Memories and analysis of memories are examined in relation to relevant social theories.

Step 1: Setting a Topic

The first step in doing memory work involves identification of a theme and/or question. Identifying the right theme is important, and adequate time should be allocated for the group to identify a theme or question of significance. As a researcher, you may set a theme or question. The question or theme needs to be written in everyday language. Haug (undated, p. 3) argues that "it is important not to pose the question in scientific or analytical terms since memories will not emerge when the appeal to them takes the form of language that is not in the vernacular. For example, 'A time when I was afraid' is common language to which everyone can relate." Further, the theme or question chosen will need to be broad enough to trigger memories while avoiding well-rehearsed memories.

Academic researchers develop their topic from experience, bodies of literature, or theory. Jansson and others (2008, p. 232) provide a clear example of how topics have been derived by researchers stating:

For instance, Widerberg (1999) started memory work on knowledge and gender by asking why she feels so uneasy in university contexts. . . In a project carried out by Bronwyn Davies et al. (2001). "Becoming Schoolgirls", the group started by discussing different theoretical concepts as a way to inspire and awake memories, and later decided to write memory stories of school experiences that actualize certain concepts.

Bryant and Livholts (2013) derived their topic for memory writing on gender, care, and the telephone by identifying key themes from the literature about telephone use and care work. Their memories were written on the theme "Where are you?" which was a common question reportedly asked by (mobile) telephone users in studies of telephone use and care (Garcia-Montes et al. 2006).

There has been discussion on how the topic chosen for writing memories influences the production of knowledge (Jansson et al. 2008). Davies et al. (2001) have argued that if theoretical concepts drive the writing of memories, there is the danger of reproducing knowledge and everyday understandings of the topic being

researched. Haug and others, recognizing that memories could simply repeat what is known, suggest that the problem under investigation should be displaced. For Haug et al. (1987), displacement of a problem means, firstly, transferring the conceptual problem to a specific situation. That is, if the concept is gendered work, then the situation might be “motherhood” or “becoming a teacher/academic etc.” Secondly, displacement of the problem involves dislocating the topic from the theoretical theme being studied, for example, Haug et al., when studying women’s sexuality, turned their focus instead to women’s bodies and hair growth. Jansson et al. (2005, pp. 232–233) explain:

In *Female Sexualization* (1987) Haug et al. describe how the group wanted to write about women’s sexuality. One of their first memory stories tells [us] about sexual assault. This story is written in a language the participants find familiar. It is a story about subordination and about women and girls lacking a sexuality of their own. The story is ‘located at the centre of the discourse in which what we understand as sexuality is produced’ (Haug et al. 1987:74). The group does not find anything they consider is “new” in...[these] kind of stories; instead they see how modes of already existing explanations and understandings are reproduced by themselves in their own stories. This in turn leads them to focus their memory stories on different parts of the female body. Now the stories do not primarily deal with sexuality, but for instance, hair growth in “wrong” places or with leg posture.

Dislocating and transferring the problem in relation to creating a topic enables different results to emerge, and as such the topic or question becomes a critical part of the methodology requiring elaboration and justification.

Step 2: Writing a Memory

During the second step, each member is required to write a detailed memory in the third person. Haug (1987) argues that writing in the third person created necessary distance to explore emotions and sensory aspects of memory. In their experience of writing memories, Jansson and others (2008, p. 235) found that “writing about oneself as ‘she’ enables us to approach this ‘she’-person with greater empathy and understanding: it is a form of textual distance that makes it possible to stay near ‘her’ and take her experiences fully seriously, in a way that is more difficult when using ‘I’.” Further, writing in the third person “is partly a way to facilitate remembering,” and some scholars suggest it makes the corporeal more readily available in memory and facilitates writing that captures the sensory and emotional aspects of experience (Jansson et al. 2008, p. 236). As such, memories should be as detailed as possible, stating emotions, color, smell, sounds in relation to an event, action, or episode. Frost et al. (2012, p. 234) suggest “they should be concrete and detailed, avoiding interpretation, biography and explanation.”

Memories should also be written in one attempt without stopping for corrections or self-censorship (Jansson et al. 2008). Writing without censorship is not always easy, requiring the writer to allow herself to be vulnerable and sharing thoughts and experiences that she may not have shared with others or has yet to share fully with herself. Having said that, writing memories is best done without censorship, and it may be appropriate at times for the memory work group to place caveats on what is

shared. For example, when teaching memory work to university students or colleagues, the purpose is not to develop theory, and as such, asking group participants to withhold details that may be upsetting to themselves or others is appropriate.

Examples of Memories

Topic: Loss of Faith (Frost et al. [2012](#))

Memory 1

Her car was hit. They sent her the bill, and when that didn't work, they tried talking to her in growling tones. She felt small, reminded of girlhood. She tried to tell herself she wasn't small; she was being made to feel that way. She called the insurance agency, making her voice sound as steady as she could. They invoiced her, and a year later, the claim is pending.

Memory 2

She is slow to rise. Caught between sitting and standing. Moments after she has stood, it registers in her mind that this is no longer automatic. As she moves bent but standing, her knees feel stiff. Rigid. Not a part of her. As she walks down the corridor, she catches a glimpse of herself in the reflection of the glass pane which separate one office from another. She is folded forward with right shoulder jutting out, her hip bones uneven. Her eyes catch her looking. She is surprised by what she sees. Always that quick half smile. She attempts to straighten and the same thought visits her on these occasions – not at work.

Step 3: Analysis and Rewriting

The third step involves members reading each other's memories and analyzing them in terms of contradictions and patterns. This process draws the individual's attention to "moments" that are often fragmented and nonlinear to enable examination of aspects of our personal lives in the context of societal structures and power relations (Haug [2008](#)). Take the example memories we provided above. Each author analyzed their own memory and their colleague's memory by seeking themes, patterns, and differences or non-patterns. For example, the author of Memory 1 reflected that her memory indicated that gender was hierarchical and when dealing with a large organization, gender and age intersect to produce differential power relations. Her colleague's analysis was similar suggesting that power was being practiced through authority and control, creating feelings about being small and not in charge. The author of Memory 2 in analyzing her memory reflected that her memory brought forth the "ideal" construct of worker that did not fit with an aging body in the workplace. Her colleague noted the liminal space between sitting and standing which reflected the lack of full acknowledgement of the body at work and how social constructions of disability linked to shame are reflected in the memory.

Apart from a broad identification of themes, analysis also involves a close focus on language used in the writing of the memory. Haug ([undated](#), p. 14) suggests that the "first step is to break from the realm of the conveyed meaning, and distance ourselves for the work of deconstruction." For Haug ([undated](#), p. 15), distancing

Table 1 Analysis of language memory 1

Verbs	Linguistic peculiarities	Named emotions	Conveyed emotions	Other people
Hit	Growling	Felt small	Girlhood	They
Talking			Made to feel = conveys pressure	Insurance company
Tried			Steady voice	

involves asking explicit questions about the language used in the text, and she suggests that all verbs be written down, all “linguistic peculiarities” be recorded (e.g., lightening in my head), emotions that have been named or conveyed be considered, and whether other people have been written into the memory should be recorded. If others are written into the memory, is there narration about them, their feelings or have they been “faded out” (undated, p. 23)? In relation to Memory 1, the following Table 1 indicates an analysis of language.

Placing words in a table shows how language is used and “how... [the author] constructs herself through language” (Haug undated, p. 16). Haug suggests that using a table like the one above will bring new observations to analysis of memories and in particular show how the writer leaves an impression for the reader. In Memory 1, for example, the words in the table show the author is being taken back to the past, to other memories of powerlessness.

In relation to both memories, analytical notes were shared at each stage of analysis and further analysis took place asking each other questions about specific words or themes. Shared meanings were developed and agreed upon. For Memory 1, the central theme was institutional gendered power and in Memory 2 the interrelationships between emotions and the social construction of the “disembodied” worker. Analysis is, however, not a linear process but as Crawford et al. (1992, p. 49) suggest happens with several readings and is recursive, that is:

The collective reflection and examination may suggest revising the interpretation of the common patterns and the analysis proceeds by moving from individual memories to the cross-sectional analysis and back again in a recursive fashion.

However, there are some assumptions in memory work about the nature of collective analysis. There is the assumption that group must reach a consensus during analysis, leaving unanswered how a diversity of views can be incorporated into analysis (Onyx and Small 2001). Stephenson (2005) has suggested that an emphasis on collectivity diminishes the examination of different and challenging ideas and, as a consequence, may also diminish some voices and stories and limit theorizing.

Analyzing memories collectively may hold a series of other challenges as analysis may cause tension, conflict, and/or distress to an individual and/or the group. In their account of reflecting on their experiences of doing memory work and collective analysis, Frost and others (2012, p. 235) explain:

In our debates and questions, we have had to manage our different epistemological orientations in a careful and respectful manner and discuss and reflect on intra-personal conflicts and interpersonal dynamics.

Further, Frost and others (2012, p. 241) provide concrete experiences of tensions when analyzing collectively and provide an example where a member of the group was not present when analysis took place feeling that her experiences were “cast aside” in how her language in the memory was analyzed.

Rewriting Memories

While Haug (1987) suggests rewriting memories, memory work groups often do not fulfill this requirement (Stephenson and Kippax 2008). In our case, the original memories were modified rather than rewritten. Minor modification of words occurred to enable reader clarity.

Haug et al. (1987, p. 245) show that the purpose of rewriting memories is to achieve a “a shift in one’s perception of one’s self and social reality” where “the individual’s active engagement in the process carries the sense of agency that comes with being an active participant in the analysis of one’s own experience.” Frost et al. provide an example whereby a participant in rewriting her memories gained agency as Haug and others hoped. Frost et al. (2012, p. 244) explain: “Her loss of faith [became] a moment of realization that she had outgrown something, which could be felt as empowering and not just as disappointing.”

Step 4: Applying Social Theories

Memory 2, when analyzed collectively, revealed an analysis of the body at work in a corporate structure and can be theorized in relation to knowledge on embodiment and work or social constructions of aging and/or disability. Taking embodiment and work, for example, Acker (1990) has argued that organizations reproduce embodied norms through structures and processes shaping organizational cultures which privilege some bodies over others. When analyses of both memories are read side by side, there is a common analytical thread around age, the body, and institutions that reflect through vision and voice dominant discourses about younger and older bodies, their power, and worth. While analysis in relation to social theory raises hegemonic discourse, the point as Stephenson (2005, p. 38) argues:

... is not to identify the imprint of hegemonic discourse in people’s experience, but to gain a better understanding of the available and emerging processes of appropriation and their effects, not only on lived experience, but on the development of a particular discourse.

Therefore, our analysis about embodiment and work for us as researcher-participants assisted us as individuals to understand the effect of discourses that may not have been apparent to us in our daily lives. In turn, this awareness provides an opportunity on a daily basis to resist or challenge self-perceptions and organizational cultures and structures. It is in this way that memory work can be transforming for individuals, as well as structurally. Haug and others have called this process of

theorizing experiences as “living historically,” that is, “what they had previously thought to be natural sequences of their lives started to appear as historically constituted avenues for interpreting and managing the material and social realities in which they were immersed” (Stephenson 2005, p. 38).

4 Memory Work and Social Transformation

Writing memories involves introspection, while analysis is likely to involve reflective and reflexive action. It is through reflexivity that transformation occurs, and as such, the concept requires interrogating. The concept of reflexivity has been understood in multiple ways (Finlay 2002; Pillow 2003). In relation to the possibility of being transformed by one’s own memory work, reflexivity involves self-scrutiny in relation to the written text, an introspective assessment of one’s experience, and assessment of social phenomena gained from the writer’s insight. Collective transformation in relation to writing and analyzing within a memory work group is more likely to occur from intersubjective reflexivity (Bryant 2015). Intersubjective reflexivity is a process where the self is co-constructed through dialogue and the multiple perspectives of other subjects (e.g., Bahktin 1981). While collective analysis and transformation may derive from subjects drawing meaning in relation to other subjects, equally difficulties may arise in reaching consensus impacting on the possibility for collective transformation.

Stephenson (2005, p. 44) drawing on Haraway (1988) brings attention to memory groups as groups consisting of “networks of actors, and choruses of multitudes. . .” Different perspectives, practices, and experiences raise the complexity of how to achieve collective understanding and/or transformation. Worldviews are shaped through our location which is situated historically, politically, socially, geographically, and culturally informed by social signifiers like age, class, sexuality, and ethnicity. Our situatedness provides the possibilities for seeing and limitations of what we see. Multidimensional ways of seeing are inherent within subjects as well as across populations of subjects. Frost et al. (2012, p. 234) discuss the interconnection between multidimensionality and collectivity in an academic memory work group stating that “despite this positive engagement and genuine sense of embarking upon a journey, we were also aware of how our different intellectual backgrounds and individual frames of reference were likely to pose problems.”

5 Ethical Considerations

Cadman et al. (2001, p. 76) believe that feminist memory work, when it allows group members to interpret the data as a whole, can bring “about some positive change in the participants and in the world.” Yet memory work that addresses trauma can also evoke distress within participants. As Fraser and Michell (2015, p. 325) argue, “care must also be taken to recruit participants and generate discussions that do not require participants to re-live their traumatic experiences in front of a non-therapeutic group.

If conducted with sensitivity, respect and adequate expertise, memory-work groups can foster levels of trustworthiness, even solidarity, among participants and researchers.” To this point, topics that are overtly traumatic for participants should be avoided (Fraser and Michell 2015).

Fraser and Michell (2015, p. 326) argue that it is key that when conducting memory work, participants are “people first and foremost, rather than sources of data.” Researchers have a duty of care for participants’ well-being and as such, should employ skilled facilitators and refer participants to support services after the session (Fraser and Michell 2015). In view of this, informed consent is a key aspect of conducting memory work ethically (Fraser and Michell 2015). Participants should receive written documentation about the project as well as being informed of their rights (especially their right to withdraw from participating at any time) and responsibilities to other participants (Fraser and Michell 2015; see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”).

Paid participation also creates complexities as it may induce a participant to become involved, tainting their free consent (Fraser and Michell 2015). For example, in a memory work study conducted by Beddoe and Jarldorn, the researchers revised \$100 participant gift cards to \$60 as the ethics committee felt that \$100 acted as “too much of an inducement to participate” (Fraser and Michell 2015, p. 328).

As Newton (2017, p. 98) writes, the key to consent is that it is ongoing: “Participants will invariably have a different understanding about the project at the beginning of the research from their understanding of it at the end. . .” As members of the group cannot anticipate what they will write in their memories, post-consent is an important ethical consideration. Post-consent forms enable group members to have time to reflect and consider what they have written and reconsider their willingness for their memories to be published.

Newton (2017, p. 98) argues that best practice for participant and researcher well-being is when researchers “reconnect with participants a little while after the research. . .to ask them of their later feelings about the research experience.” Using memory work as a method, therefore, facilitators of the group (usually researchers) will need to ensure that the time for group meetings is adequate to discuss processes and emotions as well as write and analyze memories. Given the emotional nature of writing and reading memories, it is also important that researchers facilitating the group provide space after meetings to check in with individuals and allow time for those who wish to stay back to talk about their personal experiences.

Upon publication of memory work studies, further ethical considerations such as privacy and anonymity arise. Glenda Koutroulis (2014, p. 81) discusses that despite changing names in her study to procure anonymity for her participants, one participant was concerned that her actions and descriptions would reveal her identity and create “profound implications” for her family. Publishing memories requires decisions about what to include and exclude when it comes to stories about others. In research submitted for publication, if the material is sensitive, consent will need to be obtained from those who appear in the memories or with the memory writer’s consent sensitive information or revealing details require deleting from the text (Bryant and Livholts 2013).

6 Conclusion and Future Directions

Memory work has been used in a variety of ways given the “openness” of the process since its inception by Haug and others (1987). It is an approach that can be used as autoethnography, with individual participants or in groups. The key benefits of memory work are that it taps into recalled experiences bringing to the fore experience as sensory, emotional, and embodied. Writing memories provides detail to a fragmented moment in time that might not come into being with more commonly used qualitative methods like face-to-face open or semi-structured interviews. Analyses of memories involve thematic analysis, as well as a linguistic analysis (see ► Chaps. 28, “[Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis](#),” and ► 48, “[Thematic Analysis](#)”). Combined, these forms of analyses highlight central themes which underlie what has been said and an understanding of how the author of the memory linguistically positions herself. Central to analyzing memories is relating the themes which emerged to social theories in order to uncover taken for granted understandings in subject’s lives. For Haug and others, taken-for-granted knowledge is part of “living historically” and analyses of living historically open avenues for transformation to the self, group members, and, through the agency of subjects potentially, social structures.

Memory work still remains somewhat on the margins of academic research, and as such, there is a scarcity of literature on the processes and outcomes of using memory work with different populations and subpopulations of people. Is memory work an appropriate tool when co-researching with, for example, older people or people from different class backgrounds (Onyx and Small 2001)? How useful is memory work in capturing the memories of people from diverse ethnic backgrounds whose memories might unfold in multiple linguistic structures? Would the recording of oral memories using a similar process be more useful for people who prefer to express themselves in ways other than writing? If oral memories are replaced with written ones, will the processes and outcomes change?

The “openness” of memory work provides opportunities for researchers to explore how the method might be used according to different settings and with diverse populations. Memory work remains a particularly useful method for focusing on a fragmented moment in time and “making us see things in a new way” (Widerberg 1999, p. 158). As Widerberg (1999, p. 160) suggests, “if we live our lives in episodes . . . The overall plot of the life-history that makes up . . . these episodes is something we cannot know until afterwards. Remembering is therefore not only a recounting of the past, but also a reinterpretation.” Memories bring the past to the present and through this process old memories become new ones. Memory work enables us to expand our understanding of our lives and the social worlds we inhabit.

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Traditional Survey and Questionnaire Platforms

32

Magen Mhaka Mutepfa and Roy Taper

Contents

1	Introduction	542
2	Descriptions of Traditional Surveys	543
2.1	Traditional Survey Tools	543
2.2	Non-measurement Errors	547
2.3	Measurement Errors	549
3	Comparison of Traditional Surveys and ICT-Based Surveys	551
4	The Merits and Limitations of Traditional and Online Surveys	553
5	Ethics in the Use of Sensitive Information and Questions	554
6	Strategies to Reduce Measurement Errors: Recommendations for Practice	555
7	Conclusion and Future Directions	556
	References	556

Abstract

Platforms for administering surveys have evolved in the past 20 years, and increasingly electronic platforms are utilized by many research programs. Historically, paper-and-pencil interviewing was the norm, and in recent years computer-assisted interviewing has been adopted by many. This chapter considers the questionnaire as a mode of data collection, the use of survey methods that employed paper and pencil, their merits, and limitations. It also compares traditional and online surveys, reasons for their wider adoption,

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and potential into the future. The discussion also considers ethics liabilities and strengths of data management in which either data collection platforms are used. Researchers should choose the most appropriate method depending on the topic, goals of the study, geographic region, timeframe, and budget. The issues highlighted above may need exploring through methodological research.

Keywords

Traditional surveys · Questionnaires · Online surveys · Representativeness · Social desirability · Interviewers

1 Introduction

Surveys were defined as several quantitative and qualitative research strategies or procedures used to systematically collect data from a sample through some form of invitations or appeals, such as face-to-face interviews, telephone interviews, or mail questionnaires (self-administered questionnaires) (Ponto 2015). Historically, surveys were administered by mail, and telephone, and also face-to-face (F2F). There are several ways to conduct research and collect information, but one way that is reliable is a survey, if well planned. More recently tablets, personal computers, and smartphones are being used for data collection. Internet-based surveys have become more popular than traditional surveys because of lower costs and faster modes of processing (Szolnoki and Hoffmann 2013; Kramer et al. 2014; Callegaro et al. 2017) (see also ► Chap. 76, “Web-Based Survey Methodology”).

Nonetheless, traditional surveys are more appropriate in rural and remote areas because 60% of the people living in these areas still do not have Internet access (UN News Centre 2015; Egan 2016), suggesting online surveys exclude the bulk of the population. Traditional surveys reduce the demographic discrepancies as people residing in the country can also be recruited as participants in research, increasing the validity of most studies. The UN News Centre (2015) also reported that broadband Internet had not reached billions of people living in low- to middle-income countries (LMIC), including 90% of people living in poverty-stricken countries. Information computer technology (ICT) still has to be availed to more rural and remote areas, particularly LMIC. The implication is that researchers should be able to select the most appropriate approach depending on the geographic area.

This chapter describes the utility of the traditional survey research method using paper-and-pencil tools. The questionnaire as a mode of data collection is discussed. It then considers the merits of both survey approaches (traditional and online) regarding response rate, social desirability, and sensitive questions. Finally, ethics of data management with either approach are considered. Both traditional surveys and ICT-based surveys are used in cross-sectional and longitudinal studies. Longitudinal studies include trend, cohort, and panel. Traditional surveys will be described below.

2 Descriptions of Traditional Surveys

Traditional surveys are used to provide more data on respondents, from basic demographic information (e.g., age, education) to social data (e.g., causes, activities). Survey design involves the planning of the whole survey project and the outlining of steps to take when conducting research. These are the steps that start from the formulation of the survey goals to the interpretation of the survey results. Depending on the existing state of knowledge about a problem being studied, different types of questions may be asked which require the use of different study designs (Varkevisser et al. 2003) (see examples given in Table 1).

Careful survey design can help researchers obtain the responses they want. For instance, a survey design should be limited to the extent necessary for respondents to understand questions or to stimulate the response so as to reduce measurement errors. Questionnaire design is a multistage process that requires attention to several details.

2.1 Traditional Survey Tools

The questionnaire is the primary data collection instrument in social, health, epidemiological, and other areas of research. Thus, researchers should take cognizance of question wording and sequencing, the appearance of the questionnaire, the mode of

Table 1 Survey types and examples of research questions

State of knowledge of the problem	Type of research questions	Type of survey
Knowing that a problem exists but knowing little about its characteristics or possible causes	What is the nature/magnitude of the problem?	Cross-sectional surveys
	Who is affected? How do the affected people behave?	
	What do they know, believe, and think about the problem and its causes	
Suspecting that certain factors contribute to the problem	Are certain factors indeed associated with the problem? (e.g., Is lack of preschool education related to low school performance? Is low-fiber diet related to carcinoma of the large intestines?)	<i>Analytical (comparative) studies</i>
		Cross-sectional comparative surveys
		Case-control studies
		Cohort studies
Having established that certain factors are associated with the problem: desiring to establish the extent to which a particular factor causes or contributes to the problem	What is the cause of the problem?	Cohort studies
	Will the removal of a particular factor prevent or reduce the problem? (e.g., smoking cessation, provision of safe water)	

Adopted from Varkevisser et al. (2003)

administration, and enhancing response rates to get the most out of data collection. Collection of data in traditional survey research has been laid on different methods which are the questionnaire, interview, panel survey, observation, and telephone interview. The characteristics of the target population, resources available, and sensitivity of the topic of interest determine the method of data collection chosen.

Market research has relied on explicitly given answers to survey questions for insight into people's behavior (Schoen and Crilly 2012). This is because business needs quick answers in order to make business decisions. Explicit methods comprise questionnaires, semantic differential, focus groups, in-depth interviews, thinking aloud, and rating scales. While explicit methods divulge information on motivations, values, and rational explanations, implicit methods divulge hidden and difficult information that is hard to verbalize (Nosek et al. 2011). Using both explicit and implicit methods enables comprehensiveness of research data.

The traditional survey tools will be discussed as follows: the format, validity and reliability, effect of mode of administration on data quality, and the potential biases. Traditional survey tools have their merits and limitations when compared to online survey tools. The survey tools, specifically the questionnaire, will be discussed in the section that follows.

2.1.1 Questionnaire Format and Design

The layout and design of the questionnaire have an impact on data collection (response and completion rates); therefore, they should be well planned (Bowling and Windsor 2008; McColl et al. 2001). The social exchange theory and theories of perception and cognition should be used during the physical design of a questionnaire to enable researchers to get the most from data collection (McColl et al. 2001). Social exchange theory explains the weighing of potential benefits and losses (cost-benefit analysis) obtained from a questionnaire. A good questionnaire design is one in which the benefits outweigh the costs. With regard to theories of perception and cognition, researchers take cognizance of how people may view, process, and interpret the questionnaire so as to evoke response. For instance, a highlighted section in a questionnaire stands out (attention) and allows participants to focus their interest.

Designing of traditional questionnaires should thus be customized to local circumstances and to improving data quality. An easy-to-use questionnaire reduces measurement error and the potential for nonresponse error of the research participant. Questionnaire design issues inclusive of providing a PDF version and careful use of design elements may also affect data reliability (Callegaro et al. 2017; van Gelder et al. 2010). Questionnaires should thus be explicit about the required data and data format (see Table 2).

To develop a good structured traditional questionnaire, the following steps must be followed: state the hypothesis, outline the analysis plan, and list the variables to be measured. The data analysis plan must be structured in terms of specific objectives and show the statistical tests to be used and types of variables. Nonetheless,

Table 2 Be clear about the data format

Unspecified format	Specified format
Name: Roy Tapera?	Surname: Tapera
Name: Tapera Roy?	First name: Roy
Date: 7/11/17	Date: 11/7/2017 (dd/mm/yy)
11/7/17	
November 7, 2017	
Age: 65	Age: 65 years 4 months
(What? Years or months)?	

online questionnaire data formats and methods often comprise attitude response scales, for instance, the Likert scale or semantic differential rating, as well as open-ended or multiple-choice questions (Devine and Lloyd 2012). These online questionnaire programs are more user-friendly than traditional questionnaires. Forced-choice formats, item nonresponse, and “don’t know” answers were less prevalent in online questionnaires compared to paper-and-pencil questionnaires (Marleen et al. 2010). The order of questions is also said to improve response rate. Further, partial responses in online questionnaires may be used to identify survey questions that were difficult to answer. When identified the questions may be amended to increase response rates and decrease item nonresponse.

Online questionnaires also have the advantage of fewer errors in data entry and coding because data are electronically entered and may easily be transformed into formats that are easy to analyze (Marleen et al. 2010; Callegaro et al. 2017). Online questionnaires may have skip patterns to hide irrelevant follow-up questions which is not possible with traditional paper-and-pencil questionnaires. Furthermore, visual and audio aids and pop-up windows may also be added to simplify responding by providing additional information. However, the additional features increased download time and contributed to nonresponse, thereby reducing the sample size (Marleen et al. 2010). Despite the advantages, the online questionnaires have their limitations.

2.1.2 Reliability and Validity of Traditional Survey Data

Administration of surveys should consider the aims of the study, the population under study, and the resources available to enhance the validity and reliability of the study (Wyatt 2000; McColl et al. 2001). The primary objective of a survey should be to collect reliable, valid, and unbiased data from a representative sample in a timely manner and without resource constraints. The process of responding to questions and modes of data collection has different effects on the validity and quality of data collected during research. The validity and reliability of a questionnaire are affected when the response rate is low.

Online surveys mostly use convenient samples and, according to Egan (2016), the “opt-in” bias, in which those who participate in online survey polls are already predisposed to taking them over a random sample, is lower in traditional surveys. In addition, the likelihood that participants’ demographics may differ among respondents and non-respondents is higher when the response rate to a study is low.

Traditional ratings are consistently more favorable than online survey ratings (Taylor et al. 2009; van den Berg et al. 2011; Liljeberg and Krambeer 2012), because of the low response rate. For instance, websites like “TripAdvisor” used by a minority of hotel guests are generalized, with results showing similar and conflicting findings and extreme variability. Low response rate affects the precision (reliability) of the survey, resulting in study bias, and weak external validity (generalizability) of the survey results (McColl et al. 2001; Bowling 2005).

Online questionnaires, in addition to poor questionnaire design, have larger amounts of measurement error than the traditional methods of data collection (Wyatt 2000; Brigham et al. 2009; Callegaro et al. 2017), as a result of participants not scrolling down to find all questions or answer choices and slow reading speed. However, the quality of data of online questionnaires on sensitive and private questions, such as anthropometry (Touvier et al. 2010), perceived health status (Graham et al. 2006), oral contraceptive history (Rankin et al. 2008), and substance use (Brigham et al. 2009), was high. This is mainly due to the anonymity of online questionnaires (see ► Chap. 76, “Web-Based Survey Methodology”).

Data on diet, health-related quality of life (QOL), and weight were found to be reliable in both online and traditional questionnaires (Marleen et al. 2010). Several psychological and psychiatric clinical and research scales, for example, the Edinburgh Postnatal Depression Scale (Spek et al. 2008), have been validated for Internet administration, and the results were reported to be slightly different from paper-and-pencil administration results, confirming the validity and reliability of the scales.

2.1.3 Effects of Mode of Administration on Data Quality

In selecting the mode of questionnaire administration, the availability of an appropriate sampling frame, anticipated response rate, potential from sources of bias other than nonresponse, time availability, financial budget, and other resources (e.g., equipment) should be considered. The different modes of administration comprise method of contacting participants, the media of delivering the questionnaire, and the administration of the questions (McColl et al. 2001; Bowling 2005). The traditional questionnaire uses the traditional paper-and-pencil interview (PAPI) and self-administration modes. The two modes impact the data quality differently (see Table 3); thus, the most appropriate mode should be selected.

Data quality is defined in terms of survey response rates, questionnaire item response rates, the accuracy of responses, absence of bias, and completeness of the information obtained from respondents. The mode of questionnaire administration has effects on (i) non-measurement errors (survey design, sampling frame and sampling, nonresponse, and item nonresponse) and (ii) measurement errors (survey instrument and data collection processes) (McColl et al. 2001; Bowling 2005; Bowling and Windsor 2008). Both the traditional and online questionnaires have their strengths and weaknesses.

2.1.4 Potential Biases of the Three Traditional and Online Surveys

Table 3 gives a summary of potential biases by mode of questionnaire administration of traditional and online questionnaires. However, the table should be interpreted

Table 3 Summary of potential biases by mode of questionnaire administration

Potential for	Face-to-face interviews	Telephone interviews	Self-administered, postal	Self-administered, programmed, electronic
More complete population coverage for sampling	High	Low	High	Low
Cognitive burden	Low	Great	Great	Great
Survey response	High	Low	Medium-low	Low
Item response/completion questionnaire	High	Low	Low	Low
Question order effects	Low	Low	High	Low
Response choice order effects	Moderate	High	High	High
Recall bias	Low	Low	High	High
Social desirability bias	High	High	Low	Low
Yes-saying bias	High	High	Low	Low
Interviewer	High	High	–	–
Length of verbal response/amount on information	High	Low	–	–
Willingness to disclose sensitive information	Low	Low	High	High
Respondents preference for mode of administration	High	Low	Low	Moderate

Adapted from Bowling (2005, p. 284)

with caution because findings are not always consistent, are not always based on experimental designs, and often have different topics (Bowling 2005). The table reveals that the traditional F2F interview questionnaire administration is the best mode of data collection (see bold text in table) as it comprises fewer biases when compared to the other modes.

The table also gives a summary of what is under discussion in this chapter, for instance, non-measurement errors and measurement errors.

2.2 Non-measurement Errors

Non-measurement errors comprise survey design, sampling, and response rate. Sample selection bias is lower in traditional questionnaires since sample selection is not limited to those with internet only. Nonetheless, health-related literature on the differences between responders and non-responders is inconsistent or inconclusive in most literature (McColl et al. 2001). Traditional surveys will be discussed in terms of representativeness.

2.2.1 Analysis of Traditional Surveys in Terms of Representativeness

The low statistics of internet coverage (e.g., 2% found in some sub-Saharan African countries) (UN Centre 2015) and other LMIC expose the lack of representativeness that may be portrayed by using online surveys in these low-income countries. However, the samples should be determined mainly by the type of study and validity of the method used. Szolnoki and Hoffmann (2013) compared different sampling methods in wine consumer research. The authors posited that depending on the topic, goals of the research, and the budget, all kinds of survey methods are being used to collect consumer data for research in the wine industry. A F2F and a telephone survey (comprising 2000 F2F and 1000 telephone respondents) were compared to online surveys [(quota sampling, 2000 participants) and snowball sampling (3000)] using identical questions. The F2F, telephone, and quota sampling methods were representative of the sociodemographic structure of the whole population with regard to the selected demographics of the quota sample. The snowball online survey had the least representative sample, suggesting snowballing technique was an inappropriate method for this particular study.

In the wine consumer study, traditional surveys were found to be more favorable than online surveys (Szolnoki and Hoffmann 2013). In addition, behavioral characteristics of consumers were delivered in the following order starting with the best: F2F, telephone interviews, and online quota surveys. In another previous online survey comprising 1,586 guests, 3% reported having posted a review about their August hotel stay on TripAdvisor (world's largest travel site) or a similar website (Brandt 2012). Three percent is a very small number for it is far off 10%, the most representative sample in research studies. Furthermore, only 12% of the respondents in the same study had posted a review regarding a hotel stay in the previous 12 months. The findings on TripAdvisor suggest the traditional sample did not use social media to share their experiences; therefore, the sample was not representative of the general population.

In other studies, one on air pollution in a national park by Taylor et al. (2009) and a German study by Liljeberg and Krambeer (2012) that also compared the two modes, it was found that the online sample response rate was much lower than the traditional telephone method even after controlling demographic variables. Sample sizes for online surveys may also be too small to support statistical analysis and inference (Brandt 2012). Online surveys are usually preferred by younger people, the educated, and people of high socioeconomic status (Blasius and Brandt 2010; Walker 2012). However, social media surveys enable participants to evaluate other people's responses by market researchers, which may lead to social desirability and acquiescence bias. Influence by other social media participants may be controlled by using other methods of research.

Previous findings (Fricker et al. 2005; Hoogendorn and Daalmans 2009; Taylor et al. 2009; Brandt 2012) suggest that online surveys cannot replace traditional surveys but could be used as a supplement. However, according to Szolnoki and Hoffmann (2013), proponents for traditional surveys, F2F surveys, still deliver the most representative results, and telephone surveys may be a good alternative although

they advised using a larger sample. The findings were consistent with those of the wine consumer research.

Thus, researchers should be aware that sampling error and nonresponse error distort survey results by compromising representativeness. Wright, this volume, posited that if reminder emails and easy-to-use web questionnaire formatting are used in online surveys, a diverse sample of participants may be obtained to improve representativeness (see ► [Chap. 76, “Web-Based Survey Methodology”](#)). Response rates to different modes of questionnaire administration vary by topic and in particular, complexity issues. For instance, traditional surveys may have a lower response rate than self-administered, postal, and telephone questionnaires for sensitive questions, which give rise to measurement errors.

2.3 Measurement Errors

The data collection process involves an interaction among the questionnaire, the respondent, and, in the case of F2F and telephone interviews, the interviewer (McColl et al. 2001; Bowling 2005; van den Berg et al. 2011). The interaction is affected by the pacing of the interview and the control over the order of questions by the interviewer. It is also affected by social desirability, acquiescence bias, interviewer bias, and response-choice order. Although traditional surveys have advantages of representativeness, they have higher social desirability response bias than Internet surveys. Measurement errors can jeopardize results; thus, they should be taken into account during research proceedings. The section below discusses social desirability acquiescence bias of traditional surveys.

2.3.1 Analysis of Traditional Surveys in Terms of Social Desirability and Acquiescence Bias

In traditional surveys, participants are more likely to consider social norms, morality, and ethnic values when responding to questionnaires which may result in social desirability bias. Social desirability is more prevalent in traditional survey interviews (Szolnoki and Hoffmann 2013; Zhang et al. 2017) but lower in self-administered questionnaires (Bowling and Windsor 2008; Morales-Vives et al. 2014). However, some previous researchers have reported no differences between interviewer versus self-completion modes and type of response (e.g., McColl et al. 2001).

Social desirability is a strength for online surveys as participants do not feel pressured to overreport desirable behaviors or underreport undesirable behaviors in online questionnaires (Bowling and Windsor 2008; Szolnoki and Hoffmann 2013; Callegaro et al. 2017; Zhang et al. 2017). Taylor et al. (2009) found evidence of social desirability in a study where participants agreed to pay higher rates to curb air pollution than the online sample. Further, perceived health status is likely to be exaggerated, and substance use, religion, politics, and sexual behavior are likely to be underestimated in traditional F2F or telephone interviews than in self-administered questionnaires and online surveys (Bowling and Windsor 2008; Liljeberg and

Krambeer 2012; Szolnoki and Hoffmann 2013; Callegaro et al. 2017; Zhang et al. 2017).

Unlike in traditional surveys, online responders feel less concerned about how they appear to others because feelings of anonymity and privacy are higher. Thus, researchers should consider using online surveys when the research requires sensitive information or use of traditional self-administered questionnaires where online surveys are not feasible. In addition, the use of well-trained interviewers can reduce the bias. Further, assurances of confidentiality and anonymity may reduce social desirability in traditional interview questionnaires. Furthermore, checking responses against known “facts,” indirect questioning, correlation of responses with social desirability measures, and randomized response techniques, which are feasible with large populations, may also reduce social desirability (Bowling 2005; Morales-Vives et al. 2014). Questions that have explicitly enunciated and identifiable options may also resolve the bias issue (see Table 2).

In addition to social desirability, acquiescence bias may also determine whether participants are going to answer truthfully particularly in traditional surveys. Traditional interview questionnaires have a higher agreement bias or “yes saying” (acquiescence bias) than self-administered questionnaires and online questionnaires. Age was also found to have effects on social desirability and acquiescence bias, both of which increase with age (Morales-vives et al. 2014). It is culturally easier to agree with others than disagree. However, Bowling (2005) posited that the acquiescence bias may be reduced by switching the order of responses periodically in a measurement scale (e.g., from “strongly agree–strongly disagree” to “strongly disagree–strongly agree”). In addition to acquiescence bias, interviewer bias also impacts F2F interview surveys.

2.3.2 Interviewer Bias

The three major sources of interviewer bias may be the interviewer (prejudices or asking leading questions), the respondent (may lie or evade questions), and the interview situation itself (physical and social setting). Interviewers may have a negative impact with regard to questionnaire administration. The interviewers vary in their ability to appear or sound neutral, listen, probe adequately, and use techniques to aid recall and record responses (Bowling 2005; Callegaro et al. 2017). Evasiveness (“don’t know” replies or no reply) was also found to be more common in paper-and-pencil self-administered questionnaires. Despite the interviewer differences, the negative impact can be minimized through careful training and monitoring of interviewers and analysis of responses by interviewers (to check for interviewer bias). Despite the criticism leveled against interviewers, they have several advantages in questionnaire administration.

A well-trained interviewer can help increase response and item response rates, maintain motivation with longer questionnaires, probe for responses, clarify ambiguous questions, help participants with enlarged show cards of response-choice options, use memory jogging techniques for aiding recall of events and behavior, and control the order of the questions (Bowling 2005; Callegaro et al. 2017). Further, Bowling posited that interviewers may also be trained to follow complex question

routing and skipping instructions. In addition, the personal F2F interview (auditory channel) is regarded as the least burdensome (Bowling 2005) since the participant is only required to have basic verbal and listening skills and ability to speak the same language as in the questionnaire, whereas self-administered questionnaires demand literacy and ability to follow routing instructions. This suggests the efficacy of interviewers in data collection.

The interviewers also ensure participants are motivated, answer, and record all responses correctly, which increases response rate despite the criticism they face. It is also easier to convince participants of the legitimacy of the study in person.

2.3.3 Response-Choice Order: Primacy and Recency Effects

Participants responding to self-administered questionnaires were found to select the first response option presented in a questionnaire (primacy effects). In contrast, the final response option is offered first in oral questions in F2F or telephone interviews because participants still remember and, where agreeable, are likely to select that option (recency effects) (Bowling 2005; Bowling and Windsor 2008). These tendencies lead to response-choice order effects (see Table 3). Recency effects were found to be more common among older people in Bowling's (2005) studies. Researchers should take cognizance of these effects when collecting data. The section below compares traditional and online surveys that have not been discussed in the chapter.

3 Comparison of Traditional Surveys and ICT-Based Surveys

Previous studies concurred that both traditional and online surveys are generally comparable in terms of validity and reliability and that psychological and communication measures are similar (Touvier et al. 2010; van den Berg et al. 2011). However, Zhang et al. (2017) disagree with this assertion. The assertion could be logical in high-income countries although debatable in LMIC. Internet connectivity is available mostly in Asia and the Middle East (Republic of Korea, 98%; Saudi Arabia, 94%) (UN News Centre 2015), which make up the top ten countries with Internet. Further, lowest levels of Internet access were reported to be mostly in sub-Saharan Africa, with connection available to less than 2 % of the population in Guinea, Somalia, Burundi, and Eritrea. Smartphone penetration in LMIC was also reported to be very low, for instance, in India, coverage was 22.4%, Bangladesh 5.2%, and Uganda 4% (UN News Centre 2015). The model used to assess availability of smartphones took into consideration the economic progression, demography, online population, and inequality (Poushter 2017). Further, 40 nations were found to have smartphones in high-income countries (e.g., South Korea: 88%) (Pew Research Centre 2015), making it logical to conduct online surveys in these high-income countries and traditional surveys in the poor countries.

Most recent studies on elderly caregivers in low-income countries (Mhaka-Mutepfa et al. 2014; Aransiola et al. 2017; McKoy Davis et al. 2017) in West African countries, Jamaica, and Zimbabwe had problems accessing rural and remote

populations. The authors revealed that the elderly with low income, less education, and living in non-metropolitan areas (rural) had no access to phones and Internet; therefore, it was difficult to make appointments for interviews. This kind of scenario is reported in LMIC where online platforms are not always available. Furthermore, online platforms (e.g., Facebook, Pinterest, and Snapchat) may be unavailable in certain countries (e.g., China) for legal or political reasons.

Nonetheless, Touvier et al. (2010) and van den Berg et al. (2011) found that online participants were comparable to respondents taking part in traditional surveys in terms of age, gender, income, education, and health status. The samples included caregivers that resided in urban areas with some possessing different demographics (Mhaka-Mutepfa et al. 2014). Although traditional surveys were found to have higher coverage in most studies, the administrative costs were much higher (2.5 times more) compared to online surveys (Hohwü et al. 2013; Szolnoki and Hoffmann 2013; Kramer et al. 2014). The cost for paper-based questionnaires used by Hohwü et al. (2013) was twice that of the online questionnaire surveys, confirming that online surveys are less costly. Therefore, there is a need for researchers to take cognizance of these differences to enable selection of the most appropriate survey method.

Online surveys were also not as representative or as projectable as traditional surveys (Hoogendorn and Daalmans 2009; Taylor et al. 2009). Hence, online surveys should be treated as a supplement to, rather than a substitute for, traditional surveys (Brandt 2012), even though they are cheap and readily available. In Germany, for example, 4.7% of all Internet users were found to be registered in some kind of web panel, and the response rate of these panels was about 20%, suggesting that only 1% of the Internet users in Germany could be reached by web panel surveys (Liljeberg and Krambeer 2012). Considering that Germany is a high-income country with such a low coverage, what can we make of low-income countries?

The discussion around effectiveness of online and traditional surveys has become synonymous with the nature/nurture controversy, whereby saying one is better than the other may be incorrect. Each of these methods has great merits, making it difficult to decide whether a good study is determined by the type of survey used. As of now, the authors believe that both traditional and web-based surveys are useful in research and complement each other. In addition, researchers should examine their target population carefully before selecting the most suitable method. Marleen et al. (2010) and Joan Lewis, a global consumer and market knowledge officer at Procter and Gamble, were some of the proponents of complementarity of both methods. Online surveys should be considered as alternatives to traditional surveys and as a complementary mode of data collection in research (Fricker et al. 2005; Hoogendorn and Daalmans 2009; Marleen et al. 2010; Brandt 2012).

Odds ratios were used to estimate differences in response rates between four modes of data collection: paper version questionnaire only, paper and web questionnaire, web questionnaire only, and web questionnaire and an incentive in the five Nordic countries (Denmark, Finland, Iceland, Norway, and Sweden) (Hohwü et al. 2013). The paper mode had a higher response rate (67%), and the three other modes had lower response rates. Lower response rates to online questionnaires were

also found in other studies (Kongsved et al. 2007; Zuidgeest et al. 2011), although online surveys had higher response rate for younger respondents with a mean age of 30 years (van den Berg et al. 2011). This finding supports the idea that although online questionnaires have lower response rates than traditional questionnaires, the response rates have specific demographics, for instance, the highly educated and undergraduate students (Greenlaw and Brown-Welty 2009; Poushter 2017). However, the younger respondents in van den Berg et al.'s study reported a preference for the paper-based survey questionnaire (83%) to the online one.

Despite traditional surveys having their merits, there were controversies between the F2F and telephone surveys. Previous researchers (Szolnoki and Hoffmann 2013) found differences between telephone and F2F methods (see Table 3) with regard to random digital dialing (RDD), good geographical coverage, personal interaction, and cost. The merits and limitations of both approaches to research will be discussed below.

4 The Merits and Limitations of Traditional and Online Surveys

Traditional survey methods have several key strengths which should be noted to enable selection of the most appropriate research method. The choice of using an online or traditional survey method depends on the topic, objectives, timeframe, and the budget at the researcher's disposal (McColl et al. 2001; Szolnoki and Hoffmann 2013). The types of questions and information needs also play a pivotal role in selection of the method or data sources to use for research depending on the most appropriate (Brandt 2012: see Table 1). Traditional surveys are reported to be explicitly structured, flexible, and adaptable. Design researchers use interviews and self-report questionnaires to measure consumer response to products regardless of the limitations of these "explicit" self-report methods (Schoen and Crilly 2012). Implicit methods have thus been developed to try and overcome self-report biases and obtain a more automatic measure of attitudes.

Another strength for traditional surveys is that participants are observable and environmental changes may be detected while administering them. Personal interaction and control within the traditional survey environment are also an advantage. These advantages may hamper the use of online surveys. Marleen et al. (2010) argued that although online surveys may be an attractive alternative, epidemiological research was still scarce because of major concerns with selective nonresponse and reliability of the data obtained. Further, reluctance to use online surveys because of safety and confidentiality issues may also be of concern.

However, despite the strengths mentioned for traditional surveys, they also have their own limitations. Multimedia elements, for instance, videos, that can provide more information to participants cannot be used in traditional surveys. Traditional surveys are also more time consuming because they involve setting up interviews and lengthy collection of data and sifting through the results manually. In addition, people who participate in traditional surveys may feel obliged to suit the

interviewers' time and cannot pace the interview, whereas Internet surveys can be saved and continued at a later date. However, premature termination cannot be prevented in online surveys.

A strength for online surveys is that busy people who decline telephone or F2F interviews may be willing to take surveys popping up on their computer screens (Kellner 2004). In Mhaka-Mutepfa et al.'s (2014) study, it was difficult to get busy people to sit down for interviews for a paper-and-pencil survey. The investigators eventually gave up after turning up for appointments several times to no avail. Nevertheless, relying on modes that require initiative from participants (like the pop-ups) may result in selective samples which raise concerns about nonresponse bias (Cooper 2011). Selection bias results from self-selection although traditional modes of data collection (e.g., the questionnaire) have shown little bias resulting from nonparticipation. Avidity bias (those with greater interest in the survey) may also be a factor especially in online surveys.

Another limitation for traditional surveys is unwillingness by participants to respond to sensitive questions, which will be discussed in the next section.

5 Ethics in the Use of Sensitive Information and Questions

Sensitive questions are situational and depend on the design features of the survey (Tourangeau and Yan 2007; Callegaro et al. 2017). Participants' reluctance to disclose sensitive information is increased in F2F surveys, particularly on illicit substance use and sexual and criminal behavior. Interviewers administering traditional surveys may provide more information to participants, but the participants are less likely to report the sensitive information. Previous researchers have reported that participants prefer online questionnaires to traditional questionnaires if research comprises sensitive questions (Tourangeau and Yan 2007; Mhaka-Mutepfa et al. 2014; Callegaro et al. 2017). For instance, in a traditional survey in Zimbabwe (Mhaka-Mutepfa et al. 2014), participants did not respond to the interview question on "How satisfied are you with your sex life?" in the WHOQOL-BREF questionnaire. This became a limitation because most of the grandparent carers in the study reported not having sex and those having sex were embarrassed to discuss sexual behaviors. Deleting the item from the WHOQOL-BREF scale would have reduced the validity of the measure.

A study on substance use and other stigmatized behaviors using traditional methods and Internet surveys was done (Newman et al. 2002). They found that people are more likely to respond to socially unacceptable behavior online than in traditional surveys (Tourangeau and Yan 2007; Liljeberg and Krambeer 2012; Szolnoki and Hoffmann 2013). The same authors reiterated that online surveys are more user-friendly where there is fear of embarrassment with exposure of weakness, failure, or deviancy to a stranger. In Marleen et al.'s (2010) study, the Internet response rate was higher than the F2F interview, because of the sensitive nature of their study. However, Wright (2017) and Marleen et al. (2010) posited that some participants were still uncomfortable responding to sensitive online

questions because of the belief that investigators may use people's IP address or other information to identify respondents, thereby compromising safety and confidential issues.

Despite the limitations caused by sensitive questions, traditional surveys enable a broad understanding of people's attitudes and feelings particularly when done alongside implicit surveys. It is possible to determine whether participants are overstating or understating their attitudes and feelings. True feelings may also be hidden in response to sensitive questions if participants are not convinced of confidentiality issues (e.g., abortion, homosexuality, HIV status) and are skeptical about how their data is going to be used. The techniques used for reducing item response in social desirability bias may be used to reduce item response when responding to sensitive questions. Reassurances on confidentiality and anonymity could alleviate lack of confidence in responding to sensitive questions.

6 Strategies to Reduce Measurement Errors: Recommendations for Practice

The following recommendations are suggested to reduce measurement errors during research:

- A pilot test or focus group in early stages of questionnaire development to trial the tool and aspects of the data collection protocol should be done. This helps researchers to better understand how people think about an issue or comprehend a question.
- A pilot study might give advance warning about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate or too complicated. Information on how the testing environment affects performance may also be gathered. Focus groups in the early stages of questionnaire development may also help.
- Data should be double-checked and verified.
- Statistical procedures may be used to adjust for measurement error.
- F2F surveys were found to be the most advantageous mode of data collection; therefore, careful training and monitoring of interviewers and analysis of responses by interviewers should be done to minimize the interviewers' negative impact on participants and prevent accidental introduction of errors.
- Triangulation of data across multiple measures may lead to more accurate findings.
- Enforcing the sustainable development goal (SDG) that stresses access to Information Computer Technology (ICT), particularly broadband Internet, may speed up development and human progress, resolve the digital divide, and develop knowledge societies (UN News Centre 2015), thereby increasing access to ICT. This will increase the use of online surveys in rural and remote areas not in the so distant future.

- Different modes of questionnaire administration were found to affect the quality of the data collected suggesting that all questionnaire users need to be cognizant of the potential effects of the mode of administration on their data. Although some previous researchers (e.g., Callegaro et al. 2017) reported that participants prefer online questionnaires to traditional questionnaires if research comprises sensitive questions, researchers should consider their sample, type of research, and demographics when choosing the mode of data collection. The biasing effects of mode of questionnaire administration have important implications for research methodology, the validity of the results of research, and the soundness of public policy developed from evidence using questionnaire-based research (Bowling 2005).

7 Conclusion and Future Directions

Despite the fact that advances in ICT have enabled researchers to move away from traditional surveys, the historical surveys still play an important role because of unavailability of Internet services in most LMIC. The chapter discusses the merits and limitations of using traditional surveys in research. The advantages of representativeness in populations that are not easily accessible were also discussed. In addition, the problems with social desirability and sensitive questions were also discussed. However, the discussion strengthens the view that researchers should move away from comparing social media and traditional data sources but should be able to select the most appropriate method, which is determined by the type, topic, goal, budget, timeframe, and geographic site of the research.

Each of the modes of data collection (traditional and online) methods has its comparative strengths and limitations. It is common that alternative methods and data sources may result in different or at times conflicting tales of accounts of data, suggesting the complementarity of the two methods. Paper-based surveys certainly still have their place in survey research and will always have. Nevertheless, continued advances in technology may increasingly diminish that demand, but researchers should choose the best survey method depending on appropriateness. Whatever method is used for data collection must fulfill the researcher's requirements.

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Epidemiology

33

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Contents

1	Introduction	560
2	What Is Epidemiology?	561
3	A Historical Perspective of Epidemiology	561
4	Study Design	563
4.1	Experimental Studies	564
4.2	Observational Studies	565
5	Measures of Disease Frequency	566
5.1	Prevalence	566
5.2	Incidence	567
5.3	How Does Prevalence Differ from Incidence?	568
6	Measures of Disease Association	568
6.1	Risk Ratio	568
6.2	Odds Ratio	569
7	Measures of Public Health Impact	569
7.1	Attributable Proportion	570
7.2	Population Attributable Risk	570
8	Validity in Epidemiologic Studies	570
8.1	Random Error	571
8.2	Confounding	572
8.3	Selection Bias	573
8.4	Measurement Error	573
9	Evidence Synthesis and Causation	573
9.1	Some Definitions	573
9.2	Association Versus Causation	575

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559

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10	Evidence Synthesis	577
11	Current Challenges in Epidemiology	577
12	Conclusion and Future Directions	578
	References	578

Abstract

Epidemiology is the core discipline underlying health research. Measuring health, identifying causes of ill health, and intervening to improve health are all key tenets of the discipline. Concerned with the “who,” “when,” “why,” and “where” of health, epidemiology is essential in informing clinical decision-making through evidence-based medicine. Traditionally the study of the occurrence and distribution of disease and determinants, epidemiology is a dynamic discipline that is increasingly being applied in differing disciplines, even beyond health. This chapter is designed as a basic introduction to epidemiology, the terminology used, and the principles in epidemiologic practice. Using public health as a framework, this chapter will also give an overview of both the traditional and more contemporary applications of epidemiology.

Keywords

Measures of association · Prevalence · Incidence · Observational study · Experimental study · Cohort · Case control · Cross sectional · Randomized controlled trial · Ecological study · Random error · Systematic error · Confounding · Selection bias · Measurement error

1 Introduction

This chapter outlines what epidemiology is: a historical perspective of the discipline of epidemiology and core concepts of the discipline, which, along with biostatistics and health services, is a core element of public health (Liamputtong 2016). Essentially, public health is concerned with threats to the health of the entire population rather than health of individuals. Epidemiology is often described as the cornerstone of public health research and practice for a number of reasons (Lee 2016; Graham 2017). First, epidemiology is concerned with assessment and monitoring of health problems in specified populations using sound research methodology. Second, epidemiology deals with identifying predisposing factors for health problems based on the development and testing of hypotheses established in other scientific fields such as behavioral sciences, physics, and biology to explain health-related states and events. Last, epidemiology provides the foundation for predicting the impact of specific exposures on health, which are essential in guiding policies and resource allocation for improving the health outcomes and social environments of people (Cates 1982; Friis 2017; Merrill 2015).

2 What Is Epidemiology?

The word “epidemiology” takes its origin from a combination of Greek words “*epi* meaning on or upon,” “*demos* meaning the people,” and “*logos* meaning study.” Epidemiology simply means “the study of what is upon the people” (Merrill 2017, p. 2). Many definitions of epidemiology have been proposed, but the following definition contains the basic concepts and principles of the field of epidemiology: “The study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems” (Last 2007, p. 61).

Primarily, epidemiology is concerned with the distribution of *frequency* and *pattern* of health-related states and events in a target population (Lee 2016; Graham 2017). Frequency is the number of health-related states and events (such as the number of cases of diabetes or stroke in a target population) and their relationship to the size of the population. In epidemiology, the resulting rate is more meaningful when compared to disease occurrence across different people. Pattern is the occurrence of health-related events by a person (Who is ill?), place (Where do they live?), and time (When did they become ill?). Personal characteristics may comprise sociodemographic factors related to the health-related state or event, including sex, age, educational status, and marital status. Place pattern may include urban-rural differences or geographic variation, while time pattern may be daily, weekly, monthly, seasonal, annually, or any other analysis of time that may impact health-related states or events occurrence. This characterization of health-related states or events by *person, place, and time* are within the domain of **descriptive** epidemiology (Cates 1982; Lee 2016; Graham 2017).

Epidemiologic methods are also used to identify **determinants**, which are factors that can bring change to a health condition or other defined characteristics. Examples of determinants include chemical agents (e.g., chemical carcinogens), biological agents (e.g., bacteria), and other less precise factors (e.g., a lack of physical activity) (Cates 1982; Dicker et al. 2006; Friis 2017). Health-related states or events are used in the definition of epidemiology to capture not only diseases (e.g., stroke or cholera) but also study of events such as drug abuse, injuries, behaviors, and conditions that affect the well-being of a population. Lastly, epidemiology involves applying the knowledge gained from epidemiologic investigations to guide policies and evidence-based practice. Results of epidemiologic studies can also assist individuals to make better and informed decisions about their lifestyle choices (Lee 2016).

3 A Historical Perspective of Epidemiology

The discipline of epidemiology evolved from Hippocrates of Cos (460–375 BC), who recognized that environmental factors could impact on health (Hippocrates 400 BC). John Graunt (1620–1674) measured for the first time patterns of birth, death, and disease occurrence by sex and geography and developed life tables and the concept of life expectancy (Graunt 1977). Thomas Sydenham (1624–689)

described occurrence of disease from an observational viewpoint (Lilienfeld and Stolley 1994; Friis 2017). Latterly, William Farr (1807–1883) built on Graunt's work by systematically collecting and analyzing mortality data in Britain. Additionally, Ignaz Semmelweis, Louis Pasteur, Robert Koch, Florence Nightingale, and others have made significant contributions to the discipline of epidemiology (Dicker et al. 2006; Merrill 2015; Friis 2017; Webb et al. 2017). It was not until later in the nineteenth century, however, that the distribution of disease was measured in specific populations with this work by John Snow underpinning many contemporary epidemiologic approaches, as well as being one of the fields of epidemiology's notable achievements.

John Snow was an English physician who made several innovative contributions to the field of modern epidemiology in his pioneering work in explaining the mode of transmission of cholera in London. In the mid-1840s, Snow began an epidemiologic investigation of a cholera outbreak in the Soho and Golden Square districts of London by assessing where in these areas people with cholera lived and worked. He was able to identify each residence on a map of the area, known today as a spot map, showing the geographical distribution of cholera cases (Snow 1857).

Snow believed that contaminated water was a source of infection for cholera; he marked the location of water pumps in the area on his spot map and then considered a relationship between the movement of people with cholera and the geographical location of the pumps. He found that more households with cholera were located within a short distance from Pump A (the Broad Street pump) compared to households with cholera around Pump B or C, which were located in different streets. When Snow interviewed households who lived in the Golden Square area, he found that residents avoided Pump B because it was perceived to be grossly contaminated and that Pump C location was too far for many residents. From this evidence, Snow concluded that the most likely source of infection for most people with cholera in the Golden Square area was the Broad Street pump (Pump A), the primary source of water for most residents. However, Snow observed that two separate populations in the Soho district were not profoundly affected by the cholera outbreak. Further investigation by Snow revealed that a brewery located in the area had a deep well on-site, where brewery workers living in the area collected their water – this protected them from the cholera epidemic (Snow 1855a, 1857).

Snow then obtained additional information from people with cholera epidemic on their water sources to confirm that the Broad Street pump was the primary source of the cholera outbreak. He presented his findings to the district officials that the consumption of water from the Broad Street pump (Pump A) was the most common source of infection among people with cholera. As a control measure and to prevent any reoccurrence of infection, the handle of the pump was removed, and the cholera epidemic ceased. This first cholera outbreak investigation by John Snow was an exercise in descriptive epidemiology.

In 1854, Snow examined data from another cholera outbreak in London (which had occurred in 1853), where he observed that the highest death rates were in

districts serviced by two water companies: the Lambeth Water Company and the Southwark and Vauxhall Water Company. Both companies drew water from the Thames River in London, an area susceptible to contamination from London sewerage, which flowed directly into the river. In 1852, however, the Lambeth Water Company had moved its water sources upstream of the Thames River, to an area less vulnerable to contamination. The Southwark and Vauxhall Water Company did not relocate the position of its water source. During this time, household residents in the area were free to obtain water from any water company. Based on these observations, Snow developed comparison tables on deaths by water source and subdistricts (Snow 1855b, 1857).

Snow concluded that water obtained solely upstream by the Lambeth Water Company caused limited deaths compared to water drawn from downstream in areas below sewage openings (thus vulnerable to contamination) by the Southwark and Vauxhall Water Company (Snow 1855b, 1857). This second work of Snow involved an analytical aspect of epidemiologic investigation of the cholera epidemic, as he compared death rates from cholera by water sources, either from the Lambeth Water Company or the Southwark and Vauxhall Water Company. Despite no practical knowledge of the occurrence of microorganisms, Snow was able to show through epidemiologic methods that water could serve as a medium for cholera transmission and therefore that findings from epidemiologic studies could be used to guide public health initiative (Snow 1855b, 1857).

More recently, epidemiology has informed prevention and control methods, with Doll and Hill (1950) famously establishing a clear-cut relationship between lung cancer and tobacco use in the 1950s in the British Doctors cohort study. Not all relationships are as well defined; therefore, newer epidemiologic methods that are more robustly able to establish causality are now needed to examine the multifactorial relationships that may exist between multiple exposures and disease outcomes. Major challenges exist in the areas of emerging infectious disease as well as the need to explore and act on determinants of health and disease to inform prevention and control methods.

4 Study Design

Epidemiologic studies may be of **experimental** or **observational** design. Further, epidemiologic studies are categorized as being either **analytic** or **descriptive** (Lee 2016; Graham 2017). Choosing the appropriate study design is essential in any epidemiologic investigation, as each study design has strengths and weaknesses as well as practical considerations. The simplest study designs, e.g., descriptive observational studies, aim to estimate a single risk, whereas more complex studies, e.g., cohort studies, aim to compare disease occurrence, understanding the cause of a disease or evaluation of the impact of a disease (Rothman 2012). The design of a study also guides how strong or weak the evidence from that study is (see Fig. 1), as well as the ability to make causal judgments from the evidence generated.

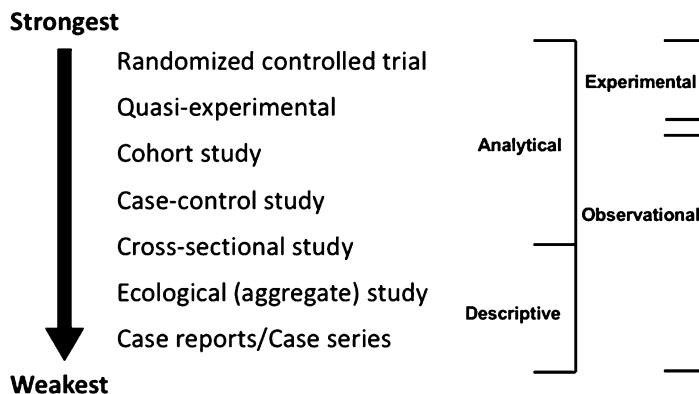


Fig. 1 Study designs

4.1 Experimental Studies

The aim of an experimental study is to intervene and change a variable in one or more groups of people. This may mean giving a drug to one group and comparing them to a control group who does not receive the drug or restricting a factor, such as dietary fat, in a group and comparing them to the control group who continues with their usual diet. While experimental studies can provide the highest level of evidence in regard to cause and effect, ethical considerations must guide their use as no patient should be denied treatment that is known to be beneficial nor should any treatment being tested that is known to be harmful (Bonita et al. 2006). Experimental studies include **randomized controlled trials** and **quasi-experimental studies** (Lee 2016; Webb et al. 2017).

- **Randomized controlled trials** (RCT) are designed to examine the effects of an intervention usually for a specific disease in the form of a clinical trial. In a RCT, participants are randomly allocated to either the intervention or control group. If randomization is conducted correctly, the only difference between the groups should be the intervention; thus this is the best way to minimize confounding (discussed in the next section) as it makes the groups exchangeable. Once allocated to either the intervention or control, individuals are followed to ascertain the effects of an intervention (see also ► [Chaps. 37, “Randomized Controlled Trials,”](#) and ► [3, “Quantitative Research”](#)).
- **Quasi-experimental studies** are similar to RCTs in that they examine the effects of an intervention. Unlike a true RCT, where treatment assignment is at random, assignment in quasi-experiments may be either by alternate allocation, by self-selection, or by administrator judgment. Because of the nonrandom nature of allocation to either intervention or control group, distinct differences in addition to the intervention itself may exist between the two groups that could influence the outcomes following intervention.

4.2 Observational Studies

Observational studies, as implied by the name, observe nature as it takes its course without any sort of intervention. Observational studies can be both descriptive and analytic. Observational **analytic** studies identify the cause of disease by analyzing the associations between exposure and outcome. An analytic study can answer the why or how questions. Almost all epidemiologic studies are analytic. Observational analytic studies include **cohort**, **case control**, and **cross-sectional analytic** studies (Lee 2016; Graham 2017; Webb et al. 2017; see also ► [Chap. 3, “Quantitative Research”](#)).

- **Cohort** studies compare the rate of disease in a group of people exposed to a factor with a group that has not been exposed. Participants in a cohort study are, therefore, selected based on their exposure status. One of the key features of a cohort study is the observation of large numbers of people over a long period of time, which can be both time-consuming and expensive, though cost can be reduced with the use of routinely collected data. Cohort studies aim to identify associations between possible risk factors or prognostic factors and the outcome of interest. One advantage of a cohort study is that a number of exposures can be measured at the same time. Cohort studies are usually prospective, where individuals are selected based on their exposure status, then followed through time to see who develops the outcome of interest. This makes measurement of the exposure less susceptible to bias when compared to a case control study. Prospective or historical cohort studies are also possible, where exposure is identified through records of past exposure, e.g., a drug exposure recorded in medical records.
- A **case control** study selects subjects on the basis of disease status with “cases” having the disease (or outcome) of interest and controls *not* having the disease (or outcome) of interest. Cases are then compared with controls with respect to past exposure history. The cases in a case control study should be representative of all cases in a specified population group (study base). The study base should be well defined in terms of time, person, and place. Controls should also be selected from the same study base and be representative of people who could become cases if they had developed the disease. One important part of a case control study is the measurement of exposure, which is done retrospectively after the development of disease. Often, this is done by direct questioning of the case or control; therefore this type of study is prone to bias (discussed in the next section).
- **Analytic cross-sectional** studies examine the association between a risk factor and an outcome. In a cross-sectional study, the exposure (or risk factor) and outcome are measured simultaneously, which can make it difficult to establish if the exposure came before or after the disease.

Descriptive studies describe the health status of a given population by person, time, and place. A descriptive study can answer the who, what, where, and when questions around the relationship between exposure and outcome. Descriptive studies are usually the first foray into an area of inquiry and are a useful way to

document the health (or illness) of a population. Generally, they are a prelude to more rigorous studies as they can only provide suggestive findings. Descriptive studies include cross-sectional (prevalence) studies, ecological studies, use of routine data, case reports, and case series (Bonita et al. 2006; Lee 2016; Graham 2017; Webb et al. 2017).

- When a **cross-sectional (prevalence) study** is descriptive, it assesses the burden of a disease in a defined population at a given point in time, like a “snapshot.”
- **Ecological studies** are aggregate or correlation studies and related exposure and outcome between populations or groups *not* individuals. Populations can be compared in different geographical areas at the same or different points in time. Many ecological studies use routine published data.
- A **case report** provides a detailed description of an unusual disease or association or a common disease in an unusual person.
- A **case series** simply aggregates individual cases into a report and may also include a hypothesis as to the cause. As with a case report, this type of study is considered to be weak evidence but may prompt further investigation with more rigorous study designs.

Practical considerations play a large part in study selection, including ethical considerations in the case of an experimental study and time/cost considerations for observational studies. Selection of study design, however, is first and foremost related to the one most appropriate for the study question. If the aim is to establish causality, the amount of bias a study is prone to must be taken into consideration.

5 Measures of Disease Frequency

In epidemiology, many different measures are used by researchers and policy decision-makers to describe the health of a specified population over a period of time. These measures allow for comparison and can be divided into two broad categories – prevalence and incidence (see also ► Chap. 3, “Quantitative Research”).

5.1 Prevalence

Prevalence measures the presence of a disease, condition, or risk factor such as smoking in a particular population at a given time. Prevalence is defined as the proportion of a population who has (or had) a specific attribute in a given time period (Merrill 2015; Lee 2016; Friis 2017; Graham 2017; Webb et al. 2017), that is:

$$\text{Prevalence} = \frac{\text{Number of existing (and new) cases}}{\text{Population at risk}}$$

Prevalence is often reported as a percentage (9% or 9 people out of 100) or as the number of cases per 10,000 or 100,000 people, depending on how common the illness or risk factor is in the population. Common types of prevalence are dependent on the time frame for the estimate:

- **Point prevalence** refers to the proportion of a population that has the disease at a specific time.
- **Period prevalence** refers to the proportion of a population that has the attribute at any point over a period of interest.
- **Lifetime prevalence** refers to the proportion of a population who at some point in life up to the time of assessment ever had the disease or attribute.

5.2 Incidence

Incidence is a measure of the likelihood of new cases of disease or injury in a population within a specified period of time (Merrill 2015; Lee 2016; Friis 2017; Webb et al. 2017), that is:

$$\text{Incidence} = \frac{\text{Number of new cases}}{\text{Time interval}}$$

Incidence is usually expressed as the proportion or rate (with a denominator) of new cases and has two main types:

- Incidence proportion (IP) or cumulative incidence (CI)
Other synonyms of IR include attack rate, risk, and probability of developing disease.
- Incidence rate (IR) or person-time rate

5.2.1 Incidence Proportion

The incidence proportion (IP) is the proportion of an initially disease-free population that develops the disease within a specified period of time. IP is a proportion because the persons in the numerator, those who develop the disease, are all included in the denominator (the total population).

$$\text{Incidence proportion} = \frac{\text{Number of new cases of disease during specified period}}{\text{Total number of the population at risk}}$$

5.2.2 Incidence Rate (IR)

The incidence rate is a measure of incidence that incorporates time directly into the denominator. IR is usually calculated from a long-term cohort follow-up study, where participants are followed over time and the occurrence of new cases of disease is documented. Like the incidence proportion, the numerator of the incidence rate is

the number of new cases identified within the period of observation. However, the denominator is different. The denominator is the amount of the time each participant was observed, totaled for all persons. This denominator represents the total time the population was at risk of and being observed for disease (Merrill 2015; Friis 2017; Webb et al. 2017). For example, in a long-term cohort follow-up study of a specific disease, each study participant may be followed or observed for several years. One person followed for 5 years without developing disease is said to contribute 5 person-years of follow-up.

$$\text{Incidence proportion} = \frac{\text{Number of new cases of disease during specified period}}{\text{Time each person was observed, totaled for all persons}}$$

5.3 How Does Prevalence Differ from Incidence?

Incidence is a measure of the number of new cases of an attribute (e.g., illness or risk factor) that is present in a population over a specific period (e.g., a month or a year), while prevalence is the proportion of a population who has (or had) a specific attribute in a given time period, irrespective of when they first developed the attribute (Merrill 2015; Friis 2017; Webb et al. 2017). The main difference between prevalence and incidence is in their numerators as the numerators of prevalence are all cases *present* within a given time period, whereas the numerators of incidence are new cases that *occurred* within a given time period.

6 Measures of Disease Association

Observational, analytical studies usually aim not only to report disease frequency but also to examine the associations between exposures (e.g., tobacco smoking) and outcomes (e.g., lung cancer). The key to these epidemiologic analyses is to compare the observed amount of disease in a population with the expected amount of disease. The comparisons can be calculated using measures of association such as risk ratio (relative risk), rate ratio, and odds ratio (Merrill 2015; Lee 2016; Friis 2017; Webb et al. 2017). Broadly, these measures provide evidence about causal relationship between an exposure and disease. However, it is important to note that association does not necessarily imply a causal relationship.

6.1 Risk Ratio

A risk ratio (RR), also called the relative risk, compares the risk of a health states or events (e.g., disease or injury) in one group with the risk in another group. Often, the two groups are differentiated by specific attributes that may

include demographic factors as sex (e.g., males vs. females) or by exposure to a potential risk factor (e.g., did or did not smoke cigarettes). The group of primary interest is usually labelled “the exposed group,” while the comparison group is labelled the “unexposed group.”

$$\text{Risk Ratio} = \frac{\text{Incidence in exposed group}}{\text{Incidence in unexposed (comparison) group}}$$

A risk ratio is interpreted where 1.0 indicates equal risk in both the exposed and unexposed groups (null value). A risk ratio greater than 1.0 shows a positive association, that is, the exposure is associated with an increased risk of the disease. A risk ratio of less than 1.0 means an inverse or negative association, that is, exposure is associated with a decreased risk of the disease, indicating that the exposure may be protective against disease occurrence.

6.2 Odds Ratio

An odds ratio (OR) also measures the association between an exposure with two categories and health outcome. The odds ratio is the measure of choice in a case-control study. In most cases, the population size from which the cases are selected is unknown. Therefore, it may be problematic calculating risk ratios from a typical case-control study. However, an odds ratio can be calculated and interpreted as an approximation of the risk ratio, particularly when the outcome is rare in the population of interest.

$$\text{Odds Ratio} = \frac{a \times d}{c \times b}$$

Where:

a = Number of persons exposed and with the disease

b = Number of persons exposed but without the disease

c = Number of persons unexposed but with the disease

d = Number of persons unexposed and without the disease

7 Measures of Public Health Impact

Measures of public health impact are used when a causal relationship has been established between exposure and an outcome. These metrics place the relationship between an exposure and a disease in a public health context and indicate the burden that an exposure contributes to the occurrence of disease in the population (Merrill 2015; Friis 2017; Webb et al. 2017). **Attributable proportion** and **population attributable risk** are two such measures.

7.1 Attributable Proportion

The attributable proportion (also called the attributable risk percent or the attributable fraction) is a measure of the public health impact of a causative factor. The calculation of this measure assumes that the occurrence of disease in the unexposed group is the baseline, that is, it allows you to calculate the *proportion* of disease in the exposed group that can be attributed to the exposure. Alternatively, this measure can be considered as the proportion of disease in the exposed group that could be prevented by eliminating the risk factor (Rockhill et al. 1998). In simple terms, the attributable proportion is the amount of disease in the exposed group attributable to the exposure. The use of attributable proportion in measuring public health impact depends on a single risk factor being responsible for a health state or event. However, when multiple risk factors may be interacting, the attributable proportion may not be appropriate.

$$\text{Attributable Proportion} = \frac{RD}{CI_e} = \frac{CI_e - CI_u}{CI_e}$$

Where:

RD = Risk difference (also called absolute risk reduction)

CI_e = Cumulative incidence in exposed group

CI_u = Cumulative incidence in unexposed group

7.2 Population Attributable Risk

The population attributable risk (PAR) is used to answer the following question: “What is the incidence of disease in a population, associated with the occurrence of the risk factor, or how much does a risk factor contribute to the overall rates of disease in groups of people?” PAR (also sometimes referred to as the population attributable fraction) is the proportional reduction in *population* disease that would occur if exposure to a risk factor were reduced to an alternative ideal exposure scenario (e.g., no physical activity). Alternatively, the attributable proportion for the entire population is the (incidence) risk in the overall population that can be attributed to the exposure.

$$\text{Population attributable risk (PAR)} = (\text{proportion of cases exposed}) \times (\text{attributable proportion in the exposed})$$

8 Validity in Epidemiologic Studies

When conducting epidemiologic research studies, the goal is accuracy in estimation where the results of the study can be generalized to the target population. The results are product of the study design itself, the study conduct, and how the data is

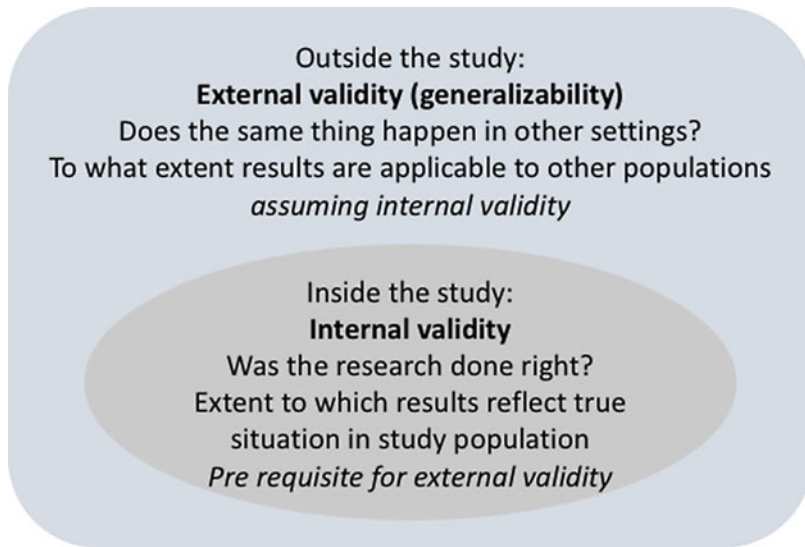


Fig. 2 Study validity

analyzed. Epidemiology is, therefore, an exercise in accurate measurement. Error is common and is classified as random (non-differential) or systematic (differential). Random error refers to a lack of precision, whereas systematic error refers to bias – an estimate that is not biased is valid. Both *internal* validity and precision are components of accuracy in an epidemiologic study. If a study is not internally valid, it cannot have *external* validity (be generalized beyond the study population – see Fig. 2). Internal validity can be affected by error in the selection of study participants, measurement of the exposure, or outcome and confounding.

8.1 Random Error

Any difference found between different groups in a study can occur due to random variation in the study subjects, meaning that the results of the study may have occurred due to chance and, therefore, differ from the true population value. This variance could be due to biological variation of individuals in a study, random sampling error, and random measurement error (Bonita et al. 2006). Random error can be minimized with adequate sample sizes. For example, if a RCT has insufficient participants, one factor may be unevenly distributed between the two groups such as age or gender. The chance of this occurring can be reduced as the number of participants increases as this reduces the amount of unevenness between the groups. Nonetheless, even when everything is constant, there will still be some random variation; therefore, we need tools to assess if any variations observed are real and important as opposed to arising by chance. Determination of random error is a key feature of statistical analyses.

A common method to assess the role of chance is hypothesis testing which produces a p values. The p value assesses whether or not findings are significantly different or not from some reference value, reflecting no effect (e.g., relative or odds ratio of one or a mean difference of zero). P represents probability, which measures the strength of the evidence against the null hypothesis and estimates how likely the difference between study groups is due to chance alone. The p value is a proportion. A smaller p indicates stronger evidence against the null and that the result is less likely due to chance. Conventionally, an arbitrary value of $p < 0.05$ is used to decide whether the results are due to chance, with a p value of <0.05 considered to be statistically significant. It should be noted, however, that the p value is not an estimate of any quantity; rather it is only a measure of the strength of evidence against the null hypothesis. The p value does not tell us anything about the size or direction of any difference. For example, in a very large clinical trial with a very small p value based on a small effect size, may not be important when translated into clinical practice.

Another value which is used to assess random variation is the confidence intervals, which is an estimate of the range of values that the true (population) value lies within. This range is the confidence interval and is commonly set at the same arbitrary level as p values (0.95) and is called the 95% confidence interval. It is important to note, however, that there is only one true value and the confidence interval defines the range where it is most likely to be. The confidence interval is not the variability of the true value or of any other value between subjects. The width of the confidence interval is important in assessing for accuracy or precision. A narrow confidence interval implies high precision, whereas a wide confidence interval implies poor precision (usually due to inadequate sample size).

8.2 Confounding

The presence of confounding can violate interval validity and introduce systematic error (bias) into a study. In epidemiology, confounding is where all or part of an apparent (observed) effect is due to some factors other than the primary exposure of interest. The result of this will mean a lack of exchangeability between exposed and nonexposed groups, which can bias the results of a study. For a factor to be a confounder, it must fulfil three criteria:

1. Be associated with both the exposure and the outcome.
2. Must be distributed unequally among the groups being compared.
3. Must *not* lie on the causal pathway between exposure and outcome.

There are several ways in which confounding can be controlled, either in the study design itself or during the analysis stage. At the study design stage, confounding can be controlled through randomization, restriction, or matching. At study analysis stage, confounding can be controlled through stratification, standardization, or multivariate modelling (Rothman 2012; Webb et al. 2017).

8.3 Selection Bias

Another type of systematic error that can introduce bias into a study is selection bias. There are several types of selection bias including volunteer bias, ascertainment or detection bias, and the healthy worker effect (Webb et al. 2017). Selection bias can also manifest in different ways in different study types. For example, in a RCT or cohort study, selection bias can occur as a result of differential losses to follow up (see ► Chap. 37, “Randomized Controlled Trials”). Once selection bias has occurred, it cannot be undone; therefore, the best way to control for selection bias is to have a rigorous study design with clear and appropriate inclusion criteria, while minimizing losses to follow-up and refusals (see also ► Chap. 3, “Quantitative Research”).

8.4 Measurement Error

The last type of error that can introduce systematic error into a study is measurement error. Also known as observation or information error, this type of bias is any error in measuring or classifying the exposure, outcome, or both. Measurement of known confounders is also prone to this type of error. The measurement error can be either differential (systematic) or non-differential (random). Differential error is when there is a difference in the measurement between the two study groups, e.g., the exposed and unexposed. Differential error can influence the effect estimate either toward or away from the null, depending on the particular error. Non-differential error is measurement error that affects both study groups and will decrease the effect size of the study, that is, bring the value closer to the null (see also ► Chap. 3, “Quantitative Research”).

9 Evidence Synthesis and Causation

9.1 Some Definitions

The principle aim of analytic (as distinct from descriptive) epidemiologic studies is to determine whether an exposure is a “cause” of an outcome. The rationale for identifying causes in epidemiology is to prevent or modify them and, therefore, prevent disease outcomes in populations. However, identifying whether an exposure is a “cause” of an outcome is often problematic, particularly in observational studies, which are always affected by bias and confounding to a greater or lesser degree (as discussed above).

There are many definitions of a “cause.” But a definition that is commonly referred to in a range of epidemiologic textbooks is by Rothman et al. (2008, p. 6): A cause is “an antecedent event, condition, or characteristic that was necessary for the occurrence of the disease at the moment it occurred, given that other conditions are fixed.” The concept of conditions that are “fixed” also relates to a more recent

interpretation of causation in contemporary epidemiology that applies the concept of the “counterfactual ideal,” summarized by Parascandola and Weed (2001, p. 906): A cause is “something that makes a difference in the outcome (or the probability of the outcome) when it is present compared with when it is absent, while all else is held constant.” Of course, this condition of *ceteris paribus* (“all things being equal”) is almost always impossible in the real world, and so epidemiologists attempt to approximate the conditions of the counterfactual ideal by using rigorous study design and accounting for bias and confounding. Epidemiologists aim to make comparison groups in a study *exchangeable* (Greenland and Robins 1986), in that the characteristics of an exposed group are the same in all respects as the unexposed group. Thus, any differences that might be observed between the “exposed” and the “unexposed” group – with all things being equal – can be attributed to that exposure factor only.

In epidemiology, “causes” are commonly classified as “sufficient,” “necessary,” or “component” causes in what has been referred to as the sufficient cause model (Rothman et al. 2008). A “sufficient” cause is a factor (or more usually a particular combination of factors) that will inevitably produce disease. A “component” cause is any component of a sufficient cause that is not an absolute requirement for the development of disease. A “necessary” cause is any sufficient cause, or component of a sufficient cause, required for the development of disease.

A useful way of conceptualizing these types of causes is the causal “pie” diagrams previously proposed by Rothman (1976). For example, Fig. 3 shows two classes of sufficient causes of a disease outcome. Sufficient cause I requires the presence of the component causes of A, B, C, D, and E, whereas sufficient cause II requires the presence of the component causes A, F, G, H, and I. The disease outcome might be ischemic heart disease, and the component causes could represent specific biological, behavioral, or environmental factors, such as “current smoking,” “obesity,” “genetics,” “physical activity,” “air pollution,” and so forth.

In this example, there are only two sufficient causes of the disease outcome. Thus, the disease will not occur due to sufficient cause I if any of the component causes A,

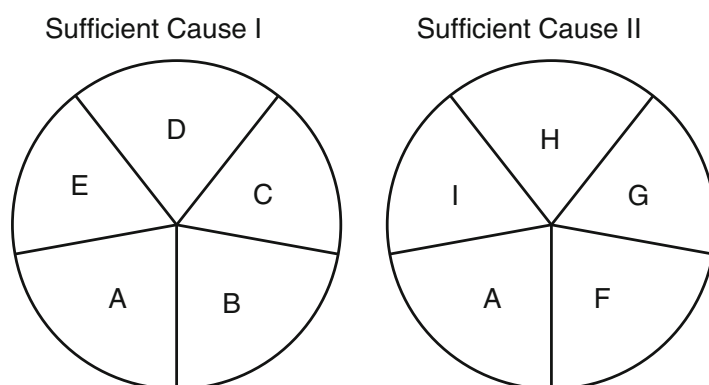


Fig. 3 Two classes of sufficient causes for a disease

B, C, D, or E are not present. Similarly, the disease will not occur due to sufficient cause II if any of the component causes A, F, G, H, or I are not present. In this example, A is a *necessary* cause for the disease, as it is present in both classes of sufficient cause. The sufficient cause model of causation implies that to prevent a given disease outcome, epidemiologists do not need to identify the *all*-component causes of disease; rather disease outcomes can be prevented by identifying single component causes.

9.2 Association Versus Causation

Analytic studies in epidemiology investigate associations between particular risk factors, or interventions, and health outcomes, and the nature of this association can be described using measures of disease frequency (prevalence, incidence) and association (relative and absolute risk), as discussed above. When epidemiologists observe an association between an exposure and an outcome (e.g., higher incidence of ischemic heart disease among current smokers compared to never smokers), the next step is to assess whether the observed association may be causal. Just because a particular exposure is associated with a disease does not automatically mean that the relationship is one of cause and effect. The observed association needs to be critically assessed in the light of how well the study was designed and implemented and how it compares with other evidence.

How might we do this? Epidemiology is an inherently *inductive* (as opposed to *deductive*) discipline – epidemiologists have hypotheses; they collect information and then arrive at conclusions based on observations. The process of induction based on repeated observation can never “prove” a hypothesis to be true. Epidemiology, like any scientific discipline, progresses through a process of elimination of bad hypotheses – a process of “conjecture” and “refutation” of hypotheses. Thus, in practice epidemiologists employ strategies to systematically evaluate whether, on balance, an observed association is more or less likely to be causal. A commonly employed framework for assessing cause and effect was proposed by Sir Austin Bradford Hill (2015). Hill proposed a series of “viewpoints” to consider when assessing an observed exposure-outcome association. Various modifications to this list have been suggested, and many elements remain cornerstones of judgment on whether an exposure is a “cause” of a disease outcome or whether an intervention is effective in treating a disease.

An abridged list of key elements of the Bradford Hill viewpoints is summarized in Table 1. “Temporality” refers to the necessity that the exposure precedes the outcome and is an inarguable criterion in assessing cause and effect. This might seem obvious; however, in practice it may not be straightforward to clearly determine whether an exposure preceded an outcome. For example, it might be observed in a study of stomach cancer that those with a diagnosis of cancer have lower levels of vitamin C. However, can we be sure that lower vitamin C levels preceded the onset of stomach cancer, or might low levels of vitamin C be a result of the disease process (Webb et al. 2017)? Establishing temporality is especially difficult, if not impossible, for

Table 1 The Bradford Hill “viewpoints”

Temporality	Does the exposure precede disease occurrence?
Strength of association	How strong is the association? What is the effect size between the exposure and the outcome?
Consistency	Is the same association evident across a range of studies and in different populations?
Dose-response	Is an increase (or decrease) in the level of exposure associated with an increase (or decrease) the level of the outcome?
Biological plausibility	Is there a plausible biological mechanism by which the exposure might cause the outcome?
Specificity	Is the exposure associated with a specific outcome or multiple outcomes?

cross-sectional study designs where information on both exposure and outcome are collected simultaneously or where exposure information is collected retrospectively.

“Consistency” refers to whether the observed association is similar to the associations observed in other studies or in different populations. If a similar association between exposure and outcome is observed across a number of studies, conducted at different points in time and using different methodologies, then the observed association is less likely to be artefactual. However, a lack of consistency with other studies does not necessarily rule out a causal relationship. Different results across studies may reflect variations in study design, measurement, or population characteristics. Consideration of sources of heterogeneity and reasons for inconsistencies across studies can also be important information in any assessing an observed association between an exposure and an outcome.

“Dose-response” refers to whether the amount (or “dose”) of the exposure is related to a change in the risk of the occurrence of the outcome. If an increase (or decrease) in the level of an exposure is associated with an increase (or decrease) in the level of the outcome, then this may be evidence for a causal association. However, the lack of a dose-response association does not necessarily preclude cause and effect, as there may be genuine cause-effect relationships where some threshold of exposure is required before it has an effect on the outcome of interest. For example, infectious diseases often have a threshold, below which the number of organisms does not cause the disease (Webb et al. 2017).

“Biological plausibility” refers to whether there is a plausible biological mechanism that can explain an observed association between the exposure and the outcome. If there is a clear biological mechanism, then this can add substantial weight to a causal argument. However, a lack of biological mechanism does not necessarily mean that the observed association is not causal. Given the complexity of human biology, it may be that a plausible biological mechanism for an observed exposure-outcome association is yet to be identified.

“Specificity” relates to the concept that a single “cause” has a single “effect.” That is, the cause is specific to that effect and not multiple effects. This does not mean that causation cannot be attributed to instances where there are multiple effects of a single cause. For example, tobacco smoking is associated with a range of poor health outcomes. However, it is not expected that a single exposure variable would be

linked to *all* outcomes. Thus, an expectation of a degree of specificity can be used to distinguish some causal hypotheses from noncausal hypotheses and whether the specificity relates to the outcome or to the exposure. For example, bicycle helmet use would be expected to reduce the risk of head injury but not other types of injury (specificity of outcome) (Webb et al. 2017), whereas a study of screening sigmoidoscopy to reduce mortality of colorectal tumors might be expected to reduce mortality-associated tumors within reach of the sigmoidoscope but not mortality from tumors located in other areas of the colon (specificity of exposure) (Rothman et al. 2008).

Importantly, each of these elements needs to be considered together. Integrating each of these perspectives can help to identify those associations that are more or less likely to be causal and the extent to which a hypothesis is sustained or refuted. This is necessarily a somewhat qualitative approach and reflects the inductivist nature of the discipline of epidemiology – ultimately whether an observed association between an exposure and outcome is causal is a matter of judgment and argument and a consideration of findings in the context of all available evidence on the topic (see Sect. 10 below). Bradford Hill (2015, p. 299) summarizes this succinctly: “Is there any other way of explaining the set of facts before us, is there any other answer equally, or more likely than cause and effect?”

10 Evidence Synthesis

While it is important to be able to appropriately interpret findings from a single study, this evidence alone is not going to provide a comprehensive picture of the effect of a given exposure on an outcome. It is important to review the literature more widely in order to identify similar patterns, and also highlight differences, across studies. A systematic review of the literature is a synthesis of *all* relevant primary research studies in response to a *focused* research question (Khan et al. 2003; Wilczynski and McKibbin 2013; see also ► Chap. 46, “Conducting a Systematic Review: A Practical Guide”).

11 Current Challenges in Epidemiology

There are numerous historical examples of epidemiologic principles being applied to population health problems (perhaps the most prominent example being John Snow’s investigation described above). However, epidemiology as a formalized discipline has emerged relatively recently in the last five to six decades. There have been many achievements of epidemiology in improving population health during this period, such as vaccination and control of infectious disease, family planning, fluoridation of drinking water, the recognition of tobacco use as a health hazard, safer work places, healthier mothers and babies, and declines in cardiovascular disease and a range of cancers, to name a few. The challenge for epidemiology is how it can continue to be useful, particularly with the emergence of chronic

disease outcomes with complex etiology in both high-income and low- and middle-income populations (Miranda et al. 2008). Causes of disease occur at macro- and microlevels of populations, and the causes of disease are inextricably intertwined with social, economic, and political environments. This is of relevance across the life course (from birth to death), within populations (from genetic to societal influences), and across populations (from one nation or culture to the next).

A “risk factor” approach to understanding disease outcomes that has commonly been employed in the past is limited in the face of this complexity (Galea et al. 2009). Single risk factors from single studies will necessarily overlook the multivariable, and often hard to measure, causes of health outcomes, particularly, chronic diseases. The tools of epidemiology, especially those relating to the design and critique of studies and evidence synthesis, are central to the interpretation of the ever-expanding evidence base in population health.

12 Conclusion and Future Directions

Epidemiology is the scientific study of the distribution (frequency, pattern) and determinants (causes, risk factors) of health-related states and events (diseases, injuries) in specified populations (people in community or health facility), and the application of this study (since epidemiology is a subfield within public health) to the control or prevent threats to population health. There is also a need for epidemiology to adapt due to the now recognized multifactorial nature of most diseases, with the standard set of approaches to be augmented by approaches that better capture the complexity of human populations. This includes the need to begin thinking in interacting *systems* of exposures, outcomes, and interventions and employing systems-level approaches that have a long history in ecology, engineering, and computer science (Galea et al. 2009; El-Sayed and Galea 2017).

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Single-Case Designs

34

Breanne Byiers

Contents

1	Introduction	582
2	Fundamentals of Single-Case Design Research	583
2.1	The Individual Case as the Unit of Analysis	583
2.2	Repeated Measurement	584
2.3	Repeated, Systematic Manipulations of the Independent Variable(S)	585
3	Baseline Logic	585
4	Matching Research Questions to Design	587
4.1	Demonstration Versus Comparison	587
4.2	Reversibility of the Target Behavior	587
5	Common Design Types	588
5.1	Demonstration Designs for Reversible Behaviors	588
5.2	Demonstration Designs for Nonreversible Behaviors	589
5.3	Comparison Designs for Reversible Behaviors	590
5.4	Comparison Designs for Nonreversible Behaviors	592
5.5	Combined Designs	592
6	Assessment of Single-Case Design Data	593
6.1	Graphical Presentation of Raw Data	593
6.2	Visual Analysis Guidelines	593
7	Other Considerations for Designing and Conducting Single-Case Research	597
7.1	Selection of Dependent Measures	597
7.2	Procedural Fidelity	598
7.3	Response-Guided Decision-Making Versus Randomization	598
8	Conclusions and Future Directions	600
	References	600

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Abstract

Single-case designs (also called single-case experimental designs) are system of research design strategies that can provide strong evidence of intervention effectiveness by using repeated measurement to establish each participant (or case) as his or her own control. The flexibility of the designs, and the focus on the individual as the unit of measurement, has led to an increased interest in the use of single-case design research in many areas of intervention research. The purpose of this chapter is to introduce the reader to the basic logic underlying the conduct and analysis of single-case design research by describing the fundamental features of this type of research, providing examples of several commonly used designs, and reviewing the guidelines for the visual analysis of single-case study data. Additionally, current areas of consensus and disagreement in the field of single-case design research will be discussed.

Keywords

Single-case designs · Single-subject designs · Small-N research · Intervention research · Idiographic research · Operant psychology

1 Introduction

Single-case designs (also called single-case experimental designs) are system of research design strategies that can provide strong evidence of intervention effectiveness by using repeated measurement to establish each participant (or case) as his or her own control. Although the methods were initially developed as tools for studying basic behavioral and physiological principles, the flexibility of the designs, and the focus on the individual as the unit of measurement, has led to an increased interest in the use of single-case design research in many areas of intervention research. Because single-case design studies do not require large numbers of participants, they can be extremely useful when the population of interest is very small or difficult to access, features that would preclude the use of large-scale randomized control trials (Rose 2017; see also ► [Chap. 37, “Randomized Controlled Trials”](#)). Further, single-case design strategies are better suited than group designs to answering research questions regarding the identification of the most effect procedures for a specific individual (or small group of people), rather than estimating an average effect within a population. Single-case design research can also be useful in the early stages of intervention development, as intervention strategies can be refined during the course of the study without compromising internal validity.

Although the term single-case implies that studies using these methods include only one participant, that is typically not the case. Some single-case designs actually require replication across participants as a form of experimental control. Even when inter-individual replication is not a design requirement, it is often

scientifically important for documenting the generality of the effect (i.e., Sidman 1960). Most published studies using single-case design methods include a minimum of three participants for this reason. Further, it should be noted that, though the “case” in single-case often refers to individual participants or organisms, this is not a necessity. It is possible to use the single-case methods to study changes in the behavior of groups of individuals. There are several examples of educational studies that have used single-case designs to evaluate changes in behavior at the classroom- or school-level (e.g., Barrish et al. 1969; Colvin et al. 1997; Putnam et al. 2003). Some researchers have even assessed changes in behavior in larger, less formal groups of individuals using the logic of single-case designs. For example, Brownell et al. (1980) examined the effects of signage on physical activity by monitoring changes in the percent of people taking the stairs in a public subway station on each day of the study. The key factors in using single-case design strategies for studying groups are the identification of a measurement scheme that will result in a single value of the group’s behavior on each measurement opportunity and documenting stability in the behavior of the group prior to implementing the intervention (both issues will be described in more detail in sections below).

The development of single-case design logic was pioneered primarily by researchers working in operant psychology in the 1960s (e.g., Sidman 1960; Baer et al. 1968). As such, many of the designs were developed to test the effects of operant behavioral principles, such as reinforcement schedules, and many of the conventions of single-case research can be traced back to that heritage. Since that time, however, single-case designs have been used to generate evidence in a range of fields, including education, social work, communication sciences, and rehabilitation studies (Rose 2017). In 2005, Horner and colleagues estimated that more than 45 scholarly journals had published single-case design studies (Horner et al. 2005).

2 Fundamentals of Single-Case Design Research

There are several key features that differentiate single-case design studies from other research methods, including quasi-experimental pre/post designs, and uncontrolled case studies. These features include: a focus on the individual case as the unit of analysis; repeated measurement of dependent variable(s); and repeated, systematic manipulations of the independent variable(s).

2.1 The Individual Case as the Unit of Analysis

In randomized controlled trials and other group-based research designs, data are most often analyzed and reported at the group level (see ► Chap. 37, “Randomized

Controlled Trials”). This means that the results reflect differences in average performance between groups; the degree to which these results represent the performance of any single individual within the group is usually unclear. In contrast, in single-case research, changes in the performance of each individual case is of primary concern. Because of this focus on the individual (as well as the small number of participants), reports of such studies typically include much more detailed descriptions of the individual participants than is possible in group studies. Further, because the research question is being answered at the individual level, single-case designs provide the opportunity to be responsive to individual differences in responding to interventions by modifying the design and intervention to achieve better results without compromising the internal validity of study (Gast and Ledford 2014; Rose 2017). See Morgan and Morgan (2014) for a more extensive comparison of the advantages and disadvantages of group and single-case design methods.

2.2 Repeated Measurement

In single-case design studies, each participant or case serves as its own control. This is achieved through repeated measurement of the dependent variable(s) within and across multiple conditions or phases. Most designs include a pre-intervention (or baseline) phase and at least one intervention phase. A post-intervention, or maintenance phase, is not uncommon in intervention research.

In a group-based intervention research, the performance of each participant is likely to be measured once at each relevant point in time (e.g., pre-intervention, post-intervention, and follow-up). This frequency of measurement is sufficient when the goal of the study is to evaluate differences in the average change in performance between groups. Although, due to measurement error and other factors, the value that each individual contributes to the group is not likely to be a perfect summary of their ability or performance in the domain of interest, if the errors are randomly distributed across members of the group, it is possible to get a reasonable estimate of group performance (and the stability of that estimate) by averaging the values from the individual members. When the distributions of the scores of two groups do not overlap, or overlap very little, there is evidence of a treatment effect. The logic of single-case design studies is similar, except that, rather than multiple measurements from individuals within a group at single points in time, the estimates of performance are based on multiple measurements within a single individual over time. By gathering multiple measurements of the individual within each phase of the study, it is possible to create a picture of how stable the individual's performance is from one measurement opportunity to the next, thereby providing a point of comparison against which to judge changes in performance due to the intervention or treatment. Because the passage of time is a key variable in single-case research, analysis of data needs to involve assessment of data patterns within and across study conditions to rule out the influence of extraneous time-related variables, such as history, repeated testing, and maturation. Ideally,

variability between measurement occasions within each phase will be limited, as changes due to treatment effects are easily detected when the distributions of the scores in each phase do not overlap with each other.

2.3 Repeated, Systematic Manipulations of the Independent Variable(S)

The logic of experimental control in single-case research goes as such: If an experimenter repeatedly makes changes to the intervention conditions (e.g., a change from the baseline condition to the intervention condition and then back again), and each change coincides with changes in the participant's performance (especially if changes are large, immediate, and consistent), this provides convincing evidence of a causal relationship between the experimenter's manipulations and the observed changes. This is because it is highly unlikely that the changes in performance were random fluctuations when they consistently occur following experimental manipulations. Many of the potential threats to the internal validity (see Shadish et al. 2002 for a thorough discussion of threats to internal validity) are no longer plausible when such effects are demonstrated multiple times. The conventionally agreed-upon minimum requirement for the number of replications is three separate manipulations, staggered over time (e.g., Kratochwill et al. 2010). As is the case in all experimental research, these manipulations need to be controlled by the experimenter – repeated observations of changes in Y following changes in X do not necessarily demonstrate a causal relationship between the two variables; changes in both might be due to changes in factor Z. By systematically manipulating X at different points in time and continuing to see the systematic variation in Y, however, the experimenter rules out the potential influence of Z (and other, potentially unidentified factors).

3 Baseline Logic

Nearly all single-case designs include a “business as usual” or baseline condition. Baseline conditions allow researchers to document the patterns of responding before any changes to the independent variable, and thereby provide a basis for extrapolation or a prediction of how responding would have continued if study conditions had not been changed. Because the goal of baseline data is to extrapolate, the ideal patterns of responding will be stable over time, with limited variability from one point to the next. Examples of useful and problematic baseline patterns are presented in Fig. 1. In each panel, the predicted patterns of performance during the subsequent intervention phase based on baseline performance are represented by the shaded bars and dashed lines. The top (A) panel shows an ideal stable baseline pattern. In panel B, there is a systematic increasing trend, which is problematic in cases where the intervention is expected to produce increases in responding, as it would make it difficult to disentangle the effects of the existing trend and any true intervention

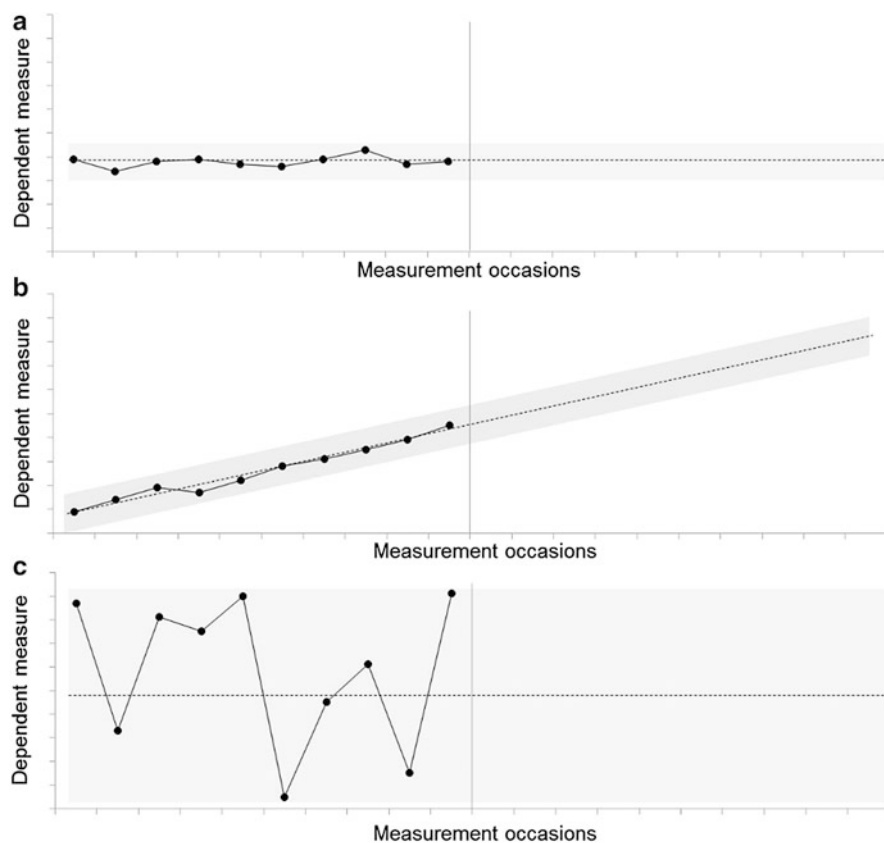


Fig. 1 Hypothetical examples of an ideal baseline data pattern (a), a baseline pattern with an increasing trend (b), and a variable baseline data pattern (c). The dashed lines represent the projected trend of performance during intervention based on the slope of the best-fitting line during the baseline phase. The shaded area represents the projected range of values

effects. If, on the other hand, the intervention was expected to produce decreases in responding, this trend would pose fewer interpretive challenges. In panel C, the wide range of values makes it difficult to predict what the next data point from the ones before, which might obscure any potential treatment effects.

Because baseline conditions are fundamental to the logic of most single-case research designs, it is essential that the researchers identify appropriate baseline conditions that will provide a reasonable test of performance under untreated conditions when designing and conducting a study. Because excessive variability in baseline performance can obscure treatment effects, researchers should consider possible sources of variability that can be controlled during all study sessions, such as changes in the time of day, location, materials present, personnel, etc.

4 Matching Research Questions to Design

In designing single-case research studies, it is essential that researchers select the appropriate research design for the specific research question and dependent variable. The first two factors to consider when making that selection are whether (a) the research question involves demonstrating the effects of a single intervention or comparing the effects of two or more interventions, and (b) the target behavior or process is reversible.

4.1 Demonstration Versus Comparison

There are two primary categories of research questions that can be answered with single-case design methodology: questions regarding whether or not a treatment or intervention condition is effective (compared to no intervention; i.e., demonstration questions), and questions regarding the relative effects of two or more treatment or intervention conditions (i.e., comparison questions). Each of these question types has a corresponding set of design strategies.

4.2 Reversibility of the Target Behavior

An additional factor distinguishing different research designs is whether it assumes the “reversibility” of the dependent variable. The analogy of the intervention or treatment as light switch is often helpful when deciding whether or not a behavior is likely to be reversible. For example, consider two pharmaceutical interventions: insulin treatment for diabetic management and antibiotics for treatment of infection. In the first case, the symptoms would be expected to be reversible: if the patient stops taking the medication, it is likely that there would be measurable changes in her/his blood sugar levels. Therefore, the medication could be used like a light switch to turn on and off the symptoms. In the second case, the symptoms being treated are likely not reversible: once the infection has been adequately suppressed by the medication, it is unlikely to return after the patient stops taking the medication. Therefore, in this case, the light switch analogy does not work, as symptoms can be eliminated but cannot be “turned back on”. Examples of reversible and nonreversible dependent variables can likely be identified in all fields of intervention research, and the expectation of reversal should be based on knowledge of the construct being studied and pilot data when available. Even when behaviors or processes should, in theory, be reversible, it may be difficult to achieve reversal in real-world contexts. For example, when interventions are being implemented by stakeholders, such as parents, teachers, or other caregivers in naturalistic environments, those stakeholders may be unable, or unwilling, to return to baseline conditions after seeing the effects of the intervention first-hand. When it is reasonable to expect that the target behavior or process being studied can be reversed, design strategies that incorporate reversals for internal validity evidence can provide the most stringent tests of experimental

control in single-case studies. Alternate design strategies for nonreversible behaviors will also be discussed below.

5 Common Design Types

5.1 Demonstration Designs for Reversible Behaviors

The ABAB Design. The ABAB design, sometimes referred to as a reversal or withdrawal design, involves alternating a baseline (A) condition with an intervention (B) condition in sequential phases. Following the initial AB demonstration of the effects of the treatment, the intervention is withdrawn in a second baseline phase, which is expected to result in a decrement in performance, which should then be reversed again in a final intervention phase. Each phase change (A to B, B to A, A to B) represents one opportunity to document a treatment effect, and as such, a successful ABAB study will result in the minimum three demonstrations of effect necessary to establish experimental control.

Figure 2 shows an example of a hypothetical ABAB study. In this example, data in the first baseline phase are relatively stable. There is an immediate change in level following the introduction of the intervention, followed by an increasing trend during the next several sessions. After performance has stabilized, the intervention is withdrawn, and an immediate change in level and trend are observed again. A large and immediate change in level occurs again in the final phase. Taken together, these results would provide strong evidence of a treatment effect as there are three, unequivocal demonstrations of the effects of manipulations of the independent variable.

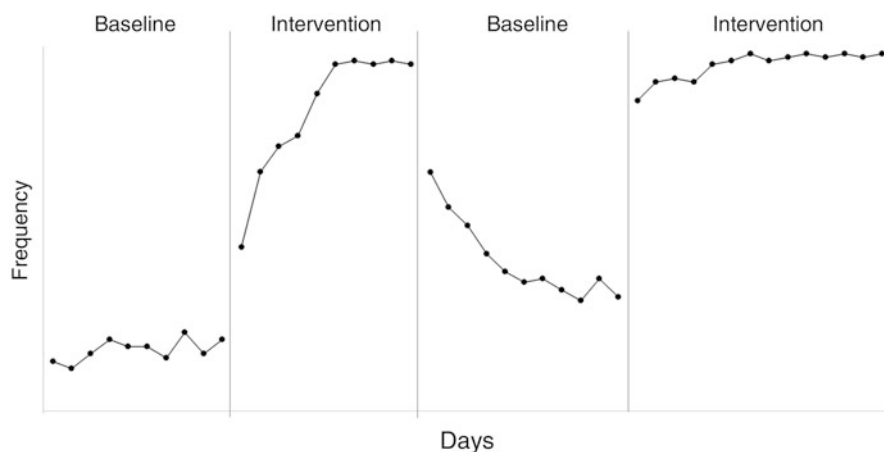


Fig. 2 Hypothetical results of an ABAB study (A = baseline condition, B = intervention condition) in which the intervention is designed to increase the frequency of the target behavior

5.2 Demonstration Designs for Nonreversible Behaviors

Multiple Baseline Design. This design is the most commonly used in contemporary intervention research (Smith 2012). One primary reason for this popularity is that the multiple baseline design does not require reversible behaviors. Instead, the multiple baseline design uses three or more separate series or baselines to provide the necessary independent demonstrations of effect. Each series may represent a different individual or case, or the effects can be replicated within a participant by selecting different target behaviors or contexts/environments. The key factors in identifying an appropriate set of series for a multiple baseline design is that (a) each needs to be expected to respond similarly to the same intervention conditions, and (b) each must be independent from the others (i.e., if the intervention is implemented in the first series, there are no concurrent changes in the others). Independence is relatively simple when each series is a separate participant but can be more challenging when series are defined by different responses, contexts, or tasks within a participant, as the likelihood that the effects of treatment for one response or in one context will affect the other responses or contexts is higher. Nevertheless, many researchers have successfully completed within-participant multiple baseline design studies that have shown strong experimental control. For example, Hersen and Bellack (1976) evaluated the effects of a social skills training package that was sequentially introduced across four target behaviors (i.e., eye contact during speech, frequency of speech disruptions, frequency of smiles, and appropriate affect) with an individual diagnosed with schizophrenia. An example of a multiple baselines across stimulus conditions was reported by Stark et al. (1990) who examined the effects of a treatment package for increasing caloric intake for children with cystic fibrosis and malnourishment that was implemented across four eating opportunities (snack and three meals).

The multiple baseline design can be conceptualized as a set of stacked AB designs, in which a baseline, or “A” phase, is followed by an intervention, or “B” phase, with no reversal replication within each series. Data collection across all of the series is conducted simultaneously, but with the intervention or treatment is introduced at different points in time across the three series to provide independent demonstrations of effect. For all of the series, data collection begins with a baseline condition. When sufficiently stable baseline data have been collected in all of the series, the intervention is implemented in the first series, and baseline data collection continues in the others. Once an effect is detected in the first series, the intervention is introduced in the second, and so on until the intervention has been implemented across all of the series.

A hypothetical multiple baseline across settings study is depicted in Fig. 3. In this case, there is a small but immediate change in level, and a change in trend observed when the intervention is introduced in Setting 1. Looking vertically across the three series, no concurrent changes occur in the other two series, which supports the assumption that the series are independent. A large immediate change is again observed when the intervention is introduced in Setting 2, with no concurrent change in the series for Setting 3. The same type of pattern is observed with the introduction of the intervention in Setting 3. Therefore, this design would provide the three

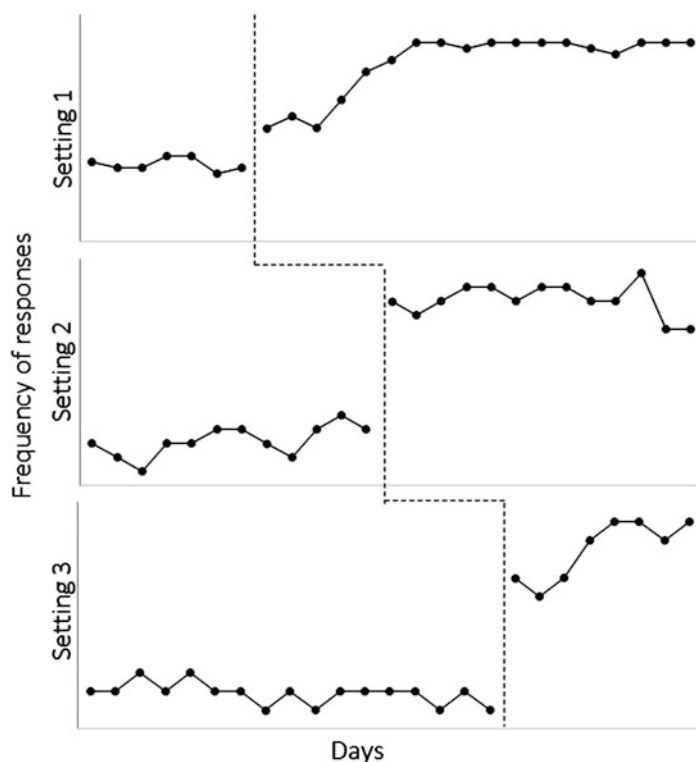


Fig. 3 Hypothetical results of a multiple baselines across settings study in which the intervention is designed to increase the frequency of the target behavior

independent demonstrations of effect across time that is necessary for demonstrating experimental control.

A potential limitation of the multiple baseline design is that the staggered introduction of the intervention results in longer baseline phases for the participants/responses/settings assigned to the lower series. In some cases, this may mean collecting dozens of data points prior to implementing any interventions or procedures, which may be resource intensive and potentially frustrating for participants, clinicians, and researchers. The multiple probe design was introduced to alleviate some of these issues by reducing the number of data collection opportunities required during the baseline phase by collecting data intermittently prior to the introduction of the intervention (see Horner and Baer 1978, for a full discussion).

5.3 Comparison Designs for Reversible Behaviors

Alternating Treatments Design. The most commonly used design for evaluating the relative effects of two or more treatment conditions is the alternating treatments

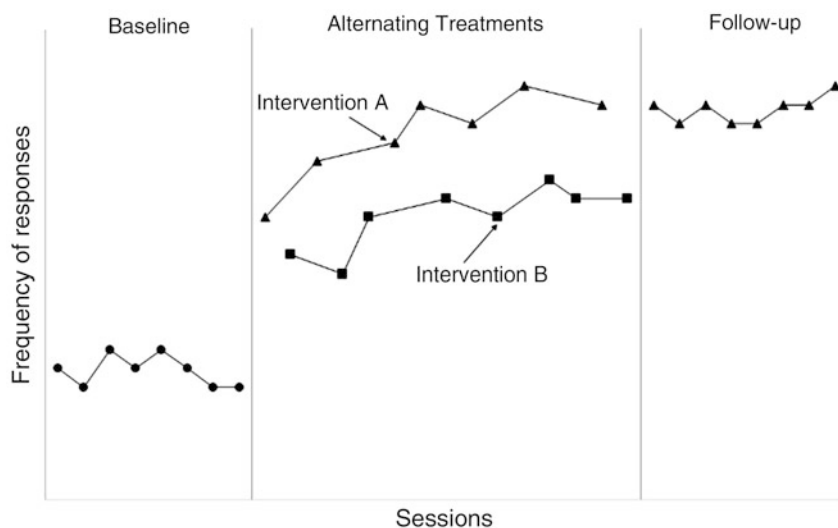


Fig. 4 Hypothetical results of an alternating treatments study comparing the degree to which two interventions increase the frequency of the target behavior relative to baseline levels and each other. This design also includes a follow-up condition evaluating the effects of the “winning” Intervention A to ensure that it remains effective without sessions of Intervention B

design (ATD; Barlow and Hayes 1979). ATD studies involve rapid and repeated manipulation of two or more conditions across observations (i.e., sessions or days), typically in a semi-randomized order. For example, Ahearn and colleagues (1996) compared the effects of two treatment packages (nonremoval of spoon and physical guidance) on food consumption among three children with chronic food refusal. The interventionists alternated between the two conditions across brief (20 spoon presentations) sessions in a semi-randomized order over several days. The results suggested that both treatments were effective in increasing food acceptance, although the physical guidance package was associated with shorter meals and was rated as more acceptable by parents.

Data from a hypothetical ATD study are presented in Fig. 4. In this example, the study begins with a baseline phase, in which responding is relatively low and stable, and continues with an alternating treatment phase, in which the two interventions (A and B) are randomly assigned to each session in the phase. Finally, a follow-up phase is conducted in which the “winning” intervention is tested alone.

The process of visual analysis for ATD studies is slightly different than in sequential phase designs, as the primary comparison of interest is between the data paths representing the two interventions within the same phase. Rather than looking for a level change between phases, visual analysts should look for separation between the data paths. In the example graph, the two data paths never cross, suggesting that performance under the conditions of Intervention A is consistently higher than those of Intervention B.

The follow-up phase, although not necessary, is recommended for this type of design, as the process of alternating between the two intervention conditions may have affect performance in one or both of the conditions, an effect called multiple treatment interference. As it is often difficult to ascertain the effects that are due to multiple treatment interference, including a follow-up phase in which only the most effective intervention is implemented over a longer period of time can be useful in demonstrating that the intervention remains effective on its own (see Higgins Hains and Baer 1989 for a more detailed discussion of this and related issues).

5.4 Comparison Designs for Nonreversible Behaviors

Adapted Alternating Treatments Designs. In the example just described, it is reasonable to assume that the response of food acceptance would be a “reversible” response, as it is likely to vary from session to session based on the intervention conditions in place. For nonreversible behaviors, however, the alternating treatments design is not a feasible design option for comparing the effects of multiple conditions. The adapted alternating treatments design (AATD; Sindelar et al. 1985) addresses this issue by assigning equivalent sets of stimulus items to each intervention or treatment condition. This design is used most frequently in educational settings to evaluate the effects of instructional practices when it is assumed that the responses being learned are not reversible. For example, Schlosser and Blischak (2004) evaluated the effects of three different feedback conditions of the spelling accuracy of four children with autism spectrum disorder. Because it was expected that the children would continue to spell each word correctly once it was learned, the researchers identified sets of target words that were of comparable difficulty to be assigned to each of the conditions for each child. By evaluating the condition associated with the fastest acquisition of the target words across sessions, the researchers were able to identify which type of feedback was most effective for each child. An important challenge for AATD studies, however, is ensuring comparability of the stimulus sets across conditions.

5.5 Combined Designs

The ways in which the more traditional single-case designs can be combined is nearly limitless. For example, in the Ahearn et al. (1996) study described in the previous section, the ATD comparison was embedded within multiple-baselines across participants design, such that the introduction of the intervention comparison phase was staggered across participants. Other studies have embedded reversal/withdrawal elements within multiple-baseline designs to provide further evidence of functional relations. See Kazdin (2011) for an extensive discussion of several additional design options for addressing different research questions.

6 Assessment of Single-Case Design Data

6.1 Graphical Presentation of Raw Data

Historically, single-case design researchers eschewed statistical analysis of data in favor of graphical presentation and visual analysis of the results. Although there is some evidence that opinions have generally shifted in favor of incorporating quantitative analyses of single-case design data in published studies, nearly all groups writing on the subject continue to support the concept that visual inspection of the raw data is an important step in the evaluation of single-case design results (e.g., Smith 2012). The conventional depiction of the data includes time (measures in sessions, days, or weeks, for example) along the horizontal axis, and the dependent measure along the vertical axis. The raw data are then plotted as individual data points for each measurement session (connected with a line within phases), and vertical lines representing changes in study conditions.

By presenting the raw data in this way, all consumers of the study results have access to all of the relevant information about participant performance. It has also been argued that using visual analysis of graphically presented data rather than relying on statistical analyses means that only large, incontrovertible effects are likely to be identified, resulting in more robust clinical interventions (i.e., Parsonson and Baer 1978). There is some evidence, however, that certain qualities of data patterns may affect the sensitivity of visual analysis, resulting in increased type I error rates (e.g., Jones et al. 1978; Matyas and Greenwood 1990; Fisch 2001), although the validity of these types of studies have been questioned by some single-case researchers (e.g., Parsonson and Baer 1992). The issues of the primacy of visual analysis, as well as its reliability, remain somewhat contentious among researchers (Manolov et al. 2014).

Although there may be some disagreement among researchers regarding whether visual analysis should be the only method of analysis for single-case experimental data, most agree that it should play a role in the interpretation of study results. As previously noted, a causal relation can be demonstrated in a single-case design study when there is a minimum of three demonstrations of changes in the dependent variable following manipulations of the independent variable. A demonstration of effect is documented when performance in one condition differs substantially from what would have been expected based on performance in the previous condition. It is important to note that, in order to minimize the potential confounding effects of time-based threats to internal validity, only data patterns from temporally adjacent phases should be compared directly, although the consistency of the results across all phases of the study should be evaluated globally.

6.2 Visual Analysis Guidelines

In his seminal textbook on single-case design methodology, Alan Kazdin (1982, p. 233) states that “in cases where intervention effects are very strong, one need not

carefully scrutinize or enumerate the criteria that underlie the judgment that the effects are veridical.” When effects are less dramatic, however, several factors need to be considered when making a judgment regarding presence and magnitude of treatment effects. Specifically, researchers and consumers should consider six major features: (1) change in level/mean, (2) change in trend, (3) change in variability, (4) immediacy of changes, (5) degree of overlap between phases, and (6) consistency of the effects across similar phases (Parsonson and Baer 1978; Kratochwill et al. 2010; Kazdin 2011; Horner et al. 2012).

Changes in mean and *changes in level* are both indicators of the magnitude of a treatment effect that refer to the changes in the value of the dependent variable between phases. Changes in mean values are fairly intuitive, as it refers to shifts in the average performance between phases. Figs. 5 and 6 both show changes in means between phases. Changes in level occur when there is a discontinuity in the data paths across phases resulting from an immediate change in the value of the dependent variable that coincides with the phase change, such as in Fig. 5. In contrast, Fig. 6 shows a change in means without a corresponding change in level, as the first data point in the intervention phase does not differ from the last data point in the baseline phase. *Trend* refers to systematic within-phase patterns of increasing or decreasing

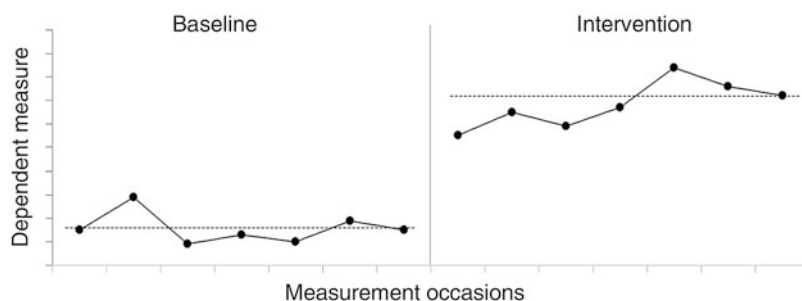


Fig. 5 Hypothetical data showing a change in means (represented by the horizontal dashed lines) and a change in level (the discontinuity identified by the arrow) between the baseline and intervention conditions

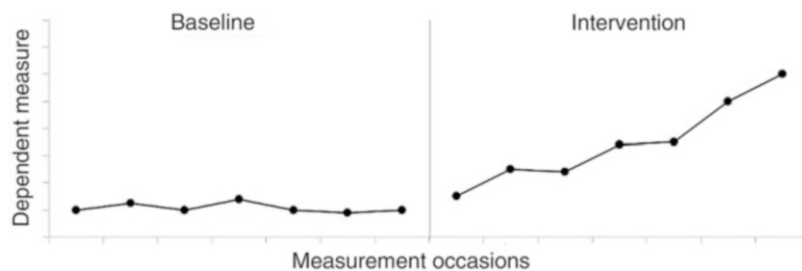


Fig. 6 Hypothetical data showing a change in trend between the baseline phase (no trend) and the intervention phase (increasing trend)

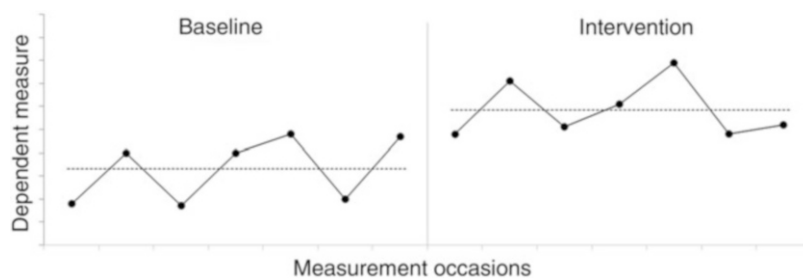


Fig. 7 Hypothetical data showing a change in means (represented by the horizontal dashed lines), but no corresponding change in level, as there is no discontinuity in the data pattern between the baseline and intervention phases

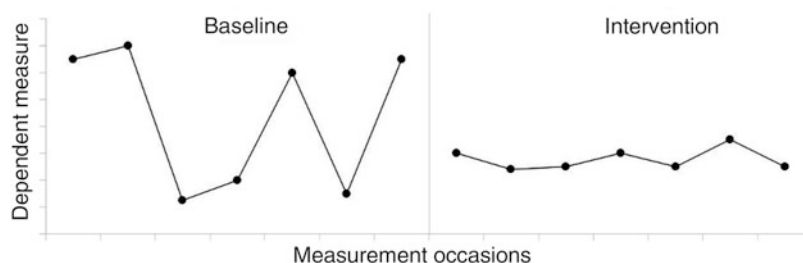


Fig. 8 Hypothetical data showing a change in variability between the baseline phase (variable) and the intervention phase (stable)

values, or the slope of the best-fitting straight line. Fig. 7 shows an example of a between-phase change in trend, as there is no trend during the baseline phase, followed by a systematic increasing trend in the intervention phase. *Variability* refers to the instability of the values of the dependent variable from one measurement point to the next, often summarized by the range or standard deviation of values within a phase. Fig. 8 shows a between-phase change in variability in which a variable pattern of responding during the baseline phase leads into a stable pattern of responding during the intervention phase (without any obvious corresponding changes in level or trend). *Immediacy of change* refers to how long it takes to see an effect following a change in phase conditions. Whereas Figs. 2, 3, 4, 5, 6, and 7 all document changes that occur immediately following a phase change; Fig. 9 shows a delayed change in level. Evidence of a treatment effect is stronger when the effects are immediate, but sometimes delayed effects are anticipated based on the nature of the behavior being evaluated. *Overlap* refers to the degree to which the range of values in one phase overlaps with the range of values from the phase against which it is being compared. For example, in Fig. 5, all of the intervention phase values fall above the range of values observed during the baseline phase. In contrast, in Fig. 8, none of the intervention phase values fall outside of the range of the baseline values, and in Fig. 6, three of the seven (43%) of the intervention phase values fall within the range

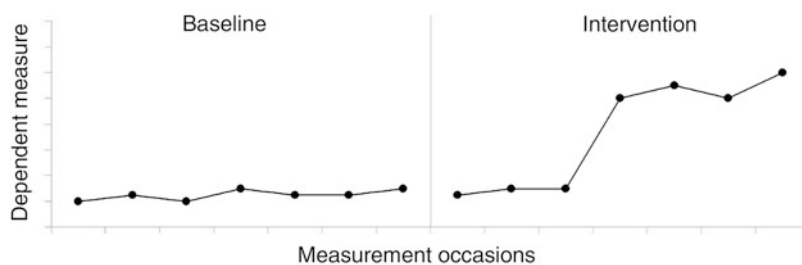


Fig. 9 Hypothetical data showing a delayed change in level during the intervention phase. Delayed effects typically reduce the confidence that any changes can be directly attributed to the effects of the intervention

Table 1 Factors to consider during visual analysis of single-case design data

Factors that increase confidence in experimental control and treatment effectiveness
Assessment of within- and between-condition data patterns
1. A sufficient number of data points in each phase/condition have been collected to allow assessment of data patterns
2. Within-phase data show limited variability
3. Baseline data show little or no trend
4. Changes in level, trend and/or variability occur immediately following manipulation of the independent variable
5. Little to no overlap in the range of values across conditions
6. The data pattern of the intervention phase(s) differ substantially from the path projected based on the baseline data
Overall results
1. There are at least three unambiguous demonstrations of the experimental effect that occur at different points in time
2. The magnitude, direction, and latency of changes are consistent across phase changes of the same type
3. The change in performance represents a clinically-meaningful improvement based on the target behavior and participant characteristics
Procedural considerations
1. Measurement of the dependent variable(s) has been adequately described and reliability data are provided
2. The independent variable (i.e., the intervention) has been adequately described, and the fidelity of implementation has been measured and reported
3. Plausible alternative explanations of the results have been considered and adequately addressed
Design-specific evidence of functional relations and treatment effectiveness
<i>Multiple-baseline designs</i>
1. There is no evidence of treatment diffusion across series: There is no evidence of changes during baseline for series in which the independent has not yet been manipulated (i.e., prior to the implementation of the intervention)
<i>Alternating treatments designs</i>
1. There is limited overlap between conditions, as defined by clear separation between data paths and few instances of data paths crossing

of the baseline values. In general, less overlap between conditions provides stronger evidence of experimental control. Finally, *consistency of the effects across similar phases* refers to the degree to which the same patterns of data are obtained every time the same type of change is made to the independent variable. For example, although the delay observed in Fig. 9 may call into question the functional relationship between the intervention and changes in the dependent variable, if this pattern of delayed effects were replicated within or across participants, this replication would minimize this concern.

All six of these features need to be considered in tandem when evaluating the results of a single-case experimental study, as treatment effects may result in simultaneous changes to multiple features of the data patterns (Table 1) (see Kratochwill et al. 2010; Kazdin 2011; Horner et al. 2012; Parsonson and Baer 1978 for more extensive discussions of the process of visual analysis).

7 Other Considerations for Designing and Conducting Single-Case Research

7.1 Selection of Dependent Measures

Selection of appropriate dependent measures is an essential component of any intervention study. In the context of single-case research, the researcher must select dependent variables that can be measured repeatedly over time, with minimal changes in performance due to repeated testing. Historically, single-case design studies have used directly observed counts of behavior as the primary dependent measures. In observational measurement, one or more members of the research team observes the study participant(s) during each scheduled study session and records the relevant feature(s), such as frequency, duration, latency, or force of the target behavior. Unlike other measurement systems, such as paper- or computer-based testing, or self-report measures, directly observed behaviors may be less prone to biases due to repeated testing when appropriate safeguards are in place. Monitoring of interobserver agreement throughout a study is one essential safeguard. This process involves having two or more trained, independent observers record data on the target behavior during a random sample of sessions during each phase. The scores from the observers are compared to ensure reliability of the measures. Several textbooks provide extensive discussions of interobserver agreement procedures (e.g., Barlow et al. 2009; Kazdin 2011; Gast and Ledford 2014).

Other sources of data can be used in the context of single-case design research, as long as the source can provide a single score for each target behavior or process for each measurement occasion, the scores produced are reliable, valid, and relatively stable over time when measured repeatedly. Wearable and remote sensors that can collect hundreds or even thousands of data points for a given metric in a day may provide an opportunity to expand the reach of single-case design research (Dallery et al. 2013). The historic focus on direct observation of behavior has meant that single-case design studies have been extremely resource-intensive to conduct: multiple

observers needed extensive training to reliably record occurrence and nonoccurrence of the target behavior, and at least one observer needed to be physically present at each measurement opportunity. With remote sensors, it may be possible to evaluate any number of clinically important variables, such as sleep quality, heart rate, physical activity, and medication adherence, among many others. Prior to implementing such measures in the context of single-case design research, however, researchers should consider the stability of the measures over time, the likelihood of participants' adhering to the use of the devices as designed, and the validity of the measures being collected.

7.2 Procedural Fidelity

Just as the measurement of the dependent variables need to be carefully operationalized and validated, implementation of the independent variable should be diligently described and documented. This includes providing detailed descriptions of the procedures in place during each of the different conditions in the study, including the baseline condition. This practice is important as interpretation of the findings of intervention research is predicated on the assumption that baseline and intervention conditions differ only by the variables relevant to the study. In addition adequate descriptions of the conditions, systematic measurement of the fidelity with which those are conditions are implemented is necessary. As described by Wolery (1994), collection of procedural fidelity data plays at least three roles in intervention research. First, it is used to monitor the occurrence of relevant variables, such that any unplanned changes in the implementation of variables can be detected. This gives researchers the opportunity to correct such shifts and may also be helpful in explaining unexpected variability in the data. Second, it provides documentation that the experimental conditions occurred as planned, which provides credibility for consumers of the research, and also facilitates replication. Finally, it provides a base from which generalizations and recommendations of the findings can be made. Specifically, by documenting procedural fidelity of an intervention, researchers can communicate with others about the conditions that need to be in effect for the intervention to have a high likelihood of success. Ledford and Gast (2014) provides a more thorough discussion of how to design and implement measurement systems for monitoring procedural fidelity.

7.3 Response-Guided Decision-Making Versus Randomization

Single-case researchers have historically used response-guided decision-making when conducting studies. Response-guided decision-making refers to using patterns in the data as they emerge to make decisions about when to make changes to the independent variable during the course of the study. The main advantage of this strategy is that the research team has the power to avoid making phase change decisions when patterns in the data might obscure treatment effects. For example,

researchers might opt to extend a baseline phase if the responding is variable or shows a trend in the direction of the expected treatment effect. Although these types of decisions frequently result in a more convincing demonstration of the effects of the intervention, it has been argued that response-guided decisions may compromise the internal validity of single-case design studies by capitalizing on chance fluctuations in the dependent variable. Specifically, it has been demonstrated that response-guided experimentation allows the researchers the opportunity for repeated visual tests of the data as they are collected, which increases the likelihood of Type I error (Allison et al. 1992).

Proponents of response-guided methods argue that the ability to be responsive to patterns in the data means that clinicians and researchers can modify treatments as needed throughout the study in order to individualize treatment components. Further, as visual analysis remains the gold standard method of analysis for single-case experimental data, some degree of responsiveness to data patterns may be necessary to avoid potential ambiguous results that can be introduced when phase change decisions are not response-guided (e.g., Ferron and Ware 1994). Many behavior-analytically oriented researchers would also argue that systematic replication alone of the effect is sufficient for experimental control, as explained by Donald Baer (1977, p. 168): “In the individual-subject paradigm, a judicious defense against chance is available. [. . .] If behavior repeated under the repeated “A’s” is repetitively different from behavior repeated under the repeated “B’s”, the scientist will conclude that such consistency cannot be a product of chance. After all, it has been repeated quite repetitively”.

Others argue that replication is insufficient to guard against the dangers of response-guided decision-making, leading several groups to call for incorporating randomization into single-case design studies (see Dugard et al. 2012; Kratochwill and Levin 2014 for more detailed discussions). As stated by Dugard et al. (2012, p. 137): “The reason why internal validity cannot be established when the timing of the intervention is response-guided is that there is no way of telling what the baseline would have looked like if it has been allowed to continue for a few more observations. We know that it probably would have appeared less stable if we had stopped it a few observations earlier; otherwise, we would have stopped it then. It might also have looked less stable if we had waited for a few more baseline observations before introducing the intervention. After all, we stopped when things seemed to be going particularly well”. Further, including randomization elements in a study design means that the data can more reasonably be subjected to inferential hypothesis tests. A full discussion of the current state of research and thinking on hypothesis testing in single-case designs is beyond the scope of the current chapter but is currently an active domain of discussion in the literature. The interested reader is referred to the 2014 special issue on analysis and meta-analysis of single-case designs in the *Journal of School Psychology* for a broad sampling of approaches and opinions (Volume 52, Issue 2).

Ultimately, the decision to use response-guided decision-making versus randomized assignment will likely depend on the goals of the research team, the research question being asked, and the training and philosophical orientation of the research

team. One potentially interesting methodological compromise involves “masked” visual analysis, in which an evaluation team who is blind to the current intervention conditions evaluates the data for potential treatment effects (e.g., Byun et al. 2017). Although intriguing, few studies using this strategy have been published to date, and additional work is needed to determine the utility of these methods in real-life intervention contexts.

8 Conclusions and Future Directions

Single-case design research can be used to address a number of different types of research questions regarding treatment effectiveness that are likely to be of interest to researchers working in clinical settings. Important quality control features of well-designed single-case design studies include an appropriate match between the research question and features of the target behavior and the design selected, reliable and valid measurement of the independent and dependent variables, and a minimum of three unequivocal demonstrations of effect that are staggered over time. Ongoing debates regarding single-case design research include whether randomization is a necessary component of all single-case design studies, and identifying the most appropriate quantitative analytic strategies for evaluating single-case design data for inferential testing and meta-analyses.

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Longitudinal Study Designs

35

Stewart J. Anderson

Contents

1	Introduction	604
2	Advantages and Problems Associated with Longitudinal Designs	605
3	Types of Longitudinal Design	606
3.1	Follow-Up Studies	606
3.2	Repeated Measures	606
4	Visualizing Repeated Measures Data	609
4.1	Motivating Example #1	609
4.2	Spaghetti and Panel Plots	609
4.3	Mean Plots	610
5	Fitting Appropriate Models to Repeated Measures Designs	612
5.1	Continuous Data	612
5.2	Models for Binary and Other Discrete Data	617
6	Discussion and Future Directions	619
	References	620

Abstract

Longitudinal study designs are implemented when one or more responses are measured repeatedly on the same individual or experimental unit. These designs often seek to characterize time trajectories for cohorts and individuals within cohorts. Three broad categories of longitudinal designs include (1) repeated measures or growth curve designs, where multiple responses for each individual are observed over time or space under the same intervention or other conditions; (2) crossover designs, where individual responses are measured over *sequences* of interventions so that individuals each “cross over” from one intervention to another; and (3) follow-up studies, where individuals in a cohort are followed

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603

until the time that they either have an “event” (e.g., death, depressive episode) or have not had an event but have no further follow-up information. Longitudinal designs may be either *randomized* where individuals are randomly assigned into different groups or *observational* where individuals from different well-defined groups are observed over time. In this chapter, I briefly discuss the nature of each of the three designs above and more deeply explore visualization and some analysis techniques for repeated measures design studies via examples of the analyses of two datasets. I conclude with discussion of recent topics of interest in the modeling of longitudinal data including models for intensive longitudinal data, latent class models, and joint modeling of survival and repeated measures data.

Keywords

Longitudinal data · Survival analysis · Repeated measures · Crossover designs

1 Introduction

Throughout the history of science, a primary philosophical goal has been to establish the cause and effect of natural phenomena (Pearl 2000). Such cause and effect mechanisms can often be established in the physical sciences where one can tightly control experimental designs and outcomes are precisely defined. However, cause and effect phenomena are not as easily established in the social, biological, and medical sciences due to the difficulty in establishing feasible outcomes, the inability to tightly control experimental conditions, and the large variability observed both across individuals and within each individual’s changing biological or clinical characteristics or state of mind (Hedeker and Gibbons 2006; Fitzmaurice et al. 2009).

A statistical study design that attempts to at least partially explain the cause and effect phenomena for the analysis of medical and biological data is called a “longitudinal” design (Hedeker and Gibbons 2006; Fitzmaurice et al. 2009). In the broadest sense, a longitudinal design is one where measurements or observations on each individual or experimental unit in a study are made at more than one (often many!!) point(s) in time. Due to the temporal nature of longitudinal designs, one may establish cause and effect in some cases, for example, how measured phenomena influence a response of interest over time. The evolution of a response may be due to aging, the effect of the intervention, or another factor.

The statistical antithesis of the longitudinal design is the *cross-sectional* design where only one measurement is made on each individual or experimental unit at some given point in time (Rosner 2010). Ideally, such designs seek to characterize a cross-section of information on one or more cohorts at an instant in time. Such designs have the advantage that they are cheaper and easier to implement. Their major disadvantage is that no cause and effect mechanism can be identified whatsoever.

It should be noted that the language used in this chapter reflects that of a broad literature concerning longitudinal statistical designs. For example, the terms outcome, response, or measurement are used in different areas of psychology, biological sciences, or medical sciences to mean the same thing. Likewise, one may use the

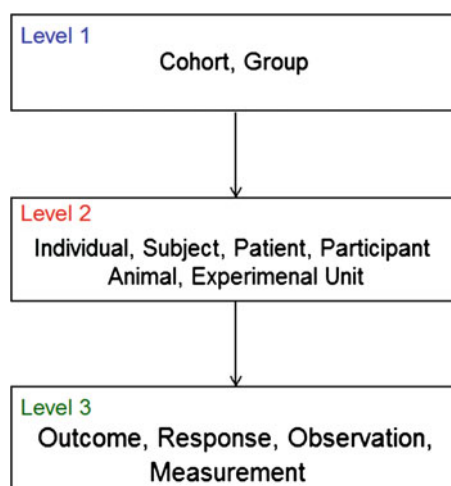
terms subject, individual, animal, experimental unit, or patient synonymously in a statistical or analytical sense. Furthermore, intervention, therapy, and treatment may also be interchangeable depending on the scientific application. What is important about these entities is their interrelationships. They follow a hierarchy, and hence, longitudinal designs are sometimes known as *multilevel* designs (see Fig. 1). The top level is the cohort or group. That level is the one that we most often wish to infer upon, for example, we may wish to infer about the differences in groups with respect to treatment, therapy, and so on. The level below that, often nested within group, is the individual. At the lowest level in most longitudinal designs is the response or outcome measured within individual. Because of the wide range of longitudinal designs, a few, e.g., crossover designs (discussed in Sect. 3.2.2), do not follow the exact hierarchy outline in Fig. 1, but almost all are associated with some degree of hierarchy (two-level, three-level, or more).

The rest of this chapter is organized as follows. In Sect. 2, some advantages and disadvantages of longitudinal designs are introduced. In Sect. 3, many types of longitudinal designs are described. In Sect. 4, a few analysis techniques are discussed. Two examples of analytical approaches are given for a repeated measures design.

2 Advantages and Problems Associated with Longitudinal Designs

Longitudinal designs have an advantage over cross-sectional designs in that they can facilitate the understanding of how different phenomena change over time. In particular, together with the use of randomization in longitudinal designs, one may detect *moderators* of intervention (therapy) effectiveness utilizing measurements unrelated to the intervention but which *precede* and are related to the response of interest (Baron and Kenny 1986; Kraemer 2013). An example is that of pre-

Fig. 1 The multilevel nature of a typical longitudinal study design



existing comorbid medical and cognitive characteristics that may moderate the effectiveness of depression interventions over time in older adults. Longitudinal designs also enable one to detect *mediators* which are variables measured *after* intervention that modify outcomes and allow insight into understanding how the variables affect or mediate the relationship between the intervention and the outcome. Such a relationship might occur in variables measuring side effects of an active therapy that may attenuate its effectiveness as compared to a placebo because of the higher incidence of the side effects in the active therapy.

From a purely statistical standpoint, longitudinal study designs have an advantage in efficiency over cross-sectional designs due to the fact that fewer subjects are needed because of the correlation of subjects across the population of interest with their own observations. Furthermore, within a cohort measured longitudinally, each subject serves as her/his own control allowing one to characterize the change of condition over time for both the at individual and cohort levels.

3 Types of Longitudinal Design

3.1 Follow-Up Studies

A very common type of design is one where one or more cohorts of individuals are measured over a period of time and the outcome of interest for each individual is the time of an “event” such as death, relapse, or depression. In some cases, individuals drop out of the study before having events, or the analysis of the data is done before all of the individuals have had events. Such occurrences prior to the event of interest are referred to as being “censored.”

These types of studies, while technically longitudinal in nature, form their own unique category known as survival or follow-up studies because the measurement of interest for each individual is often a single entity, namely, the time to event or censor. Due to issues of power, these studies are often employed in very large cohorts that are observed over long periods of time. Many involve population studies comparing individuals with different demographic, biological, or clinical characteristics or large clinical studies where individuals are randomized to receive different treatments, interventions, or therapies. I do not elaborate further in this chapter about this type of study, but excellent references are available that detail their design and analysis (see Kalbfleisch and Prentice 2002; Klein and Moeschberger 2003).

3.2 Repeated Measures

3.2.1 Classic Repeated Measures and Growth Curve Designs

One of the most common types of longitudinal designs is one where each member of one or more cohorts is followed over a long period of time under the same conditions (Fleiss 1986; Hedeker and Gibbons 2006). The “same conditions” here means that the members within each cohort have the same treatment or intervention or have the

same characteristics (e.g., same gender or same level of depression or some other characteristic to be tested). Consequently, each subject only has one treatment or characteristic of interest. Since subjects within each cohort share the same treatment or characteristic and are associated with only one such treatment or characteristic, their individual effects are said to be “nested within” the treatment or characteristic effect.

If the period of measurement is long enough, measurements within subject tend to have correlation structures that do not widely vary over time. In other cases, where the time frame is short, measurements that are closer together tend to be more highly correlated than those that are farther apart in time.

With the advent of technology to rapidly monitor measurements within individuals, an adaptation of the growth curve design is that of intensively measured longitudinal studies (Wallis and Schafer 2006). The purpose of such studies is to repeatedly measure hundreds or thousands of measurements over either a short or a long period of time to detect both gross and subtle patterns of change. Like the standard growth curve design, each unit or subject is measured under the same condition or treatments. Examples of this type of design are cardiac studies that monitor patient output each second over several hours or days and studies that use electronic diaries to monitor physical and behavioral activity over time.

The ideal design for growth curve studies is to have each subject measured at equally spaced times. Of course, ideally, one would not want to have any missing measurements. Unfortunately, in human or animal studies, individuals do not show up for visits, or they show up several days or weeks after their scheduled visits, or they withdraw or die before the end of the study or a whole host of other things that can happen over time. Moreover, there are certain studies where measurements cannot be observed at regular times due to situations beyond the experimenters’ control. Such studies can produce irregularly spaced data.

3.2.2 Crossover Designs

Another type of longitudinal study design is called a “crossover design” (Grizzle 1965; Fleiss 1986; Brown and Prescott 2006). In this type of design, individuals are typically randomized to receive a *sequence* of treatments. Thus, instead of being assigned to a single treatment group, each unit is usually assigned to receive all of the treatments, but different individuals may be assigned to have these treatments in a different sequence. An example of a two-period crossover design is depicted in Fig. 2. As one can see, each subject receives a sequence of treatments A and B. When an individual has completed one treatment, they go through a “washout period” before receiving the next treatment. This guards against what is known as a carryover effect so that the effect of each treatment can be uniquely distinguished. For example, if treatment A is given in the second period, we would want to ensure that effects of treatment B on the outcome of interest had not “carried over.” Otherwise, possible differences in the effects would be attributed to the previous treatment and hence, the sequence that individuals were assigned to rather than the treatments themselves. Of course, crossover designs are not limited to two periods and two treatments, and there are many variations where there are many periods and with all treatments being received by each individual or some subset of treatments

	Period 1	Washout Period	Period 2
Subject 1	Treatment A		Treatment B
Subject 2	Treatment B		Treatment A
⋮	⋮		⋮
Subject i	Treatment B		Treatment A
Subject i+1	Treatment A		Treatment B
⋮	⋮		⋮

Fig. 2 Schema of a two-period crossover design

being received by each individual. What is common to all crossover designs is that washout periods are necessary between periods and individuals are typically randomized to receive *sequences of treatments* rather than a single treatment. Crossover designs evolved from an earlier incarnation in agriculture studies known as permuted block or Latin square studies (Fleiss 1986).

Crossover designs are appropriate when a disease or condition is *chronic* (e.g., “endogenous” depression, essential hypertension, Fleiss 1986). In this case, the period of administration of the treatment is short as compared to the duration of the condition or disease. Furthermore, crossover designs work best when there is little or no residual or *carryover effect* of a treatment after an appropriate washout period. If, in fact, there are *small* carryover effects of the treatments, then those effects should be close to the same for both treatments. It is not appropriate to use crossover designs when a condition or disease being treated is acute such as with postoperative pain, short-term depression, or a short-term illness like a cold or short-term flu. Crossover designs are also not effective when the residual effects of the treatments are so long that individuals will drop out of the study or if the residual effects of the treatments are either large or vary by treatment group or both.

Crossover studies have a desirable feature that longitudinal growth curve studies do not have in that each participant of the study can receive more than one or possibly all of the treatments being tested (Grizzle 1965; Fleiss 1986). Like the longitudinal growth curve studies, increased precision is obtained by the multiple measurements on an individual being made, and confounding is reduced because each patient serves as his or her own control. However, the potential carryover effect associated with a crossover study is always worrisome, and hence, crossover studies may be difficult to implement because of the complexity of the design. Furthermore, results from crossover studies can be somewhat difficult to

interpret even when carryover effect is not present. Finally, like other longitudinal studies, dropouts and missing data are problematic. In crossover studies, a large number of dropouts are particularly troublesome. Sometimes, a complete period of treatment must be dropped due to bias. This can force a longitudinal study to be analyzed as if it were cross-sectional, thus losing the advantages of having repeated observations.

A recent design innovation somewhat related to crossover designs involves *adaptive* designs (Lavori and Dawson 2000; Murphy 2003, 2005). These designs usually involve individuals being randomly assigned to a therapy, being followed (measured) over time, and then, at a particular decision point, being reassigned to a different or the same therapy depending upon whether they were responsive to the original therapy. A study where individuals are randomized to a strategy involving both initial therapies and then re-randomized to receive other therapies depending on their response to the initial therapy is called sequential multiple assignment randomized trial (SMART) (Murphy 2005). What distinguishes a SMART study from a crossover study is that in the former, the sequential strategy is adapted to the response of each individual, whereas in the latter, the sequential treatment pattern is assigned without regard to patient or subject response.

4 Visualizing Repeated Measures Data

One important step that is sometimes forgotten by a busy analyst is to visualize the data. It is useful to do this before formal analyses are performed. Luckily, with modern software, there is an extraordinary amount of routines that allow us to visualize data in many different ways (Anderson 2011). In the sections below, I introduce a couple of simple types of plots that can be quite useful in understanding our data and properly interpreting the formal analyses that we perform on repeated measures data.

4.1 Motivating Example #1

To motivate plotting of repeated measures data, I refer to a famous data set, first presented by Potthoff and Roy (1964) and later by many other authors. The data involve measurements in millimeters (mm) of the distance from the center of the pituitary to the pteryomaxillary fissure in 27 children taken at ages 8, 10, 12, and 14 years by investigators at the University of North Carolina Dental School. Sixteen of the study cohorts were boys and 11 were girls. By the standards of modern investigation, this is a relatively small study. Questions of interest involved characterizing the growth patterns in both cohorts and comparing the growth patterns between genders.

4.2 Spaghetti and Panel Plots

One useful type of plot of these data involves the display of the boys' and girls' trajectories of measurements overlaid over time as interpolated curves (Fig. 3). This

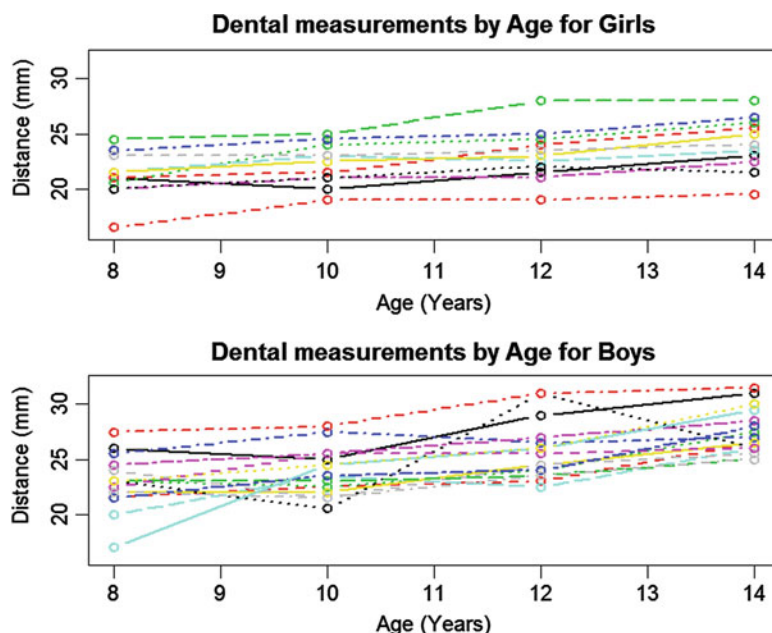


Fig. 3 Spaghetti plots of boys' and girls' dental measurements (Potthoff and Roy 1964)

can enable us to view general patterns in the two cohorts and possibly identify outliers if they exist.

Another useful visualization of repeated measures data is that of *panel plots* where each individual's data is plotted on a graph and then the cohort(s) of individuals are stacked together so that one can view the variability of the trajectories of individuals within the cohort(s) being studied. Panel plots of the dental measurements of each individual boy and girl for the Potthoff and Roy data are presented in Fig. 4.

Both spaghetti and panel plots are very useful for getting a sense of the data in small studies and for identifying potential outliers or influence points in the data. However, one disadvantage of spaghetti and panel plots is that, for larger studies, individual variation leads to morass visualization of the information so that patterns averaged (or summarized) over a cohort are difficult to discern. In such cases, plots of summarized data can be explored (see next section).

4.3 Mean Plots

Another type of useful plot where measurements are on a continuous scale and made over time on each individual within a study is that of means plus or minus either their standard errors (SEM) or means and their pointwise 95% confidence intervals. If data are approximately normally distributed, such plots facilitate the interpretation of statistical inference about one or more cohorts (see Fig. 5 for our example data).

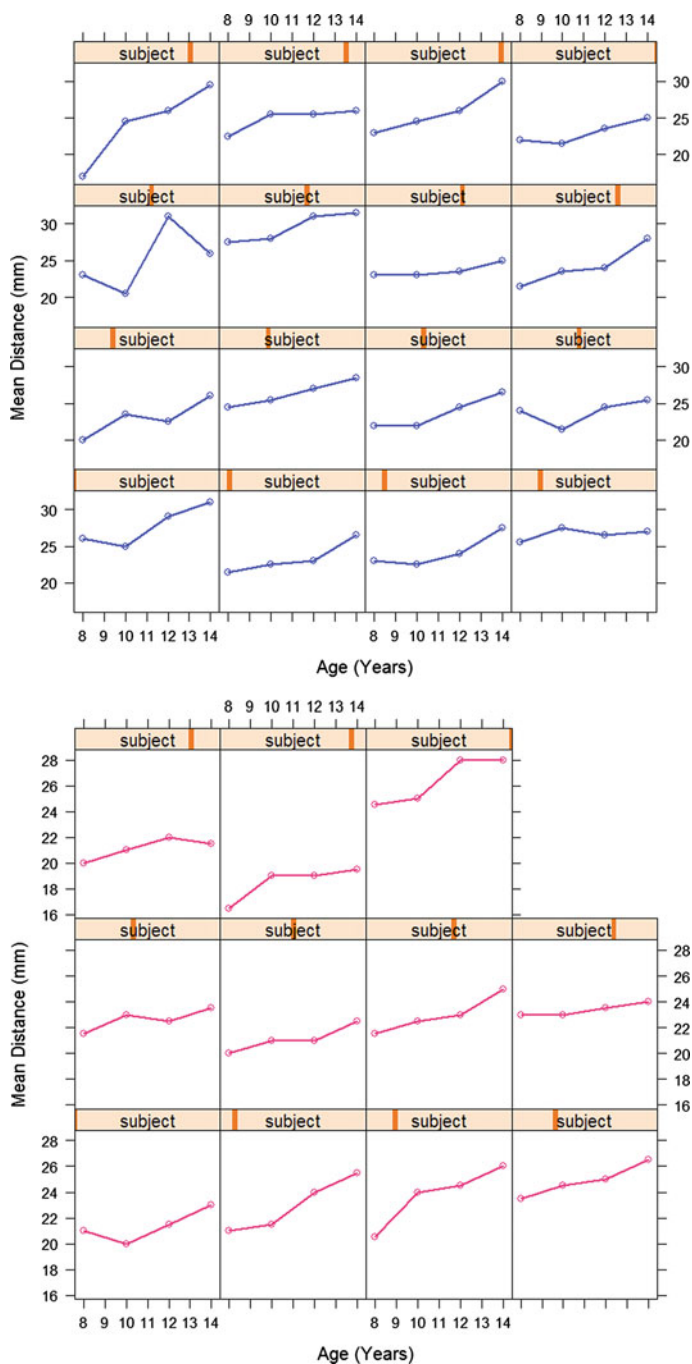
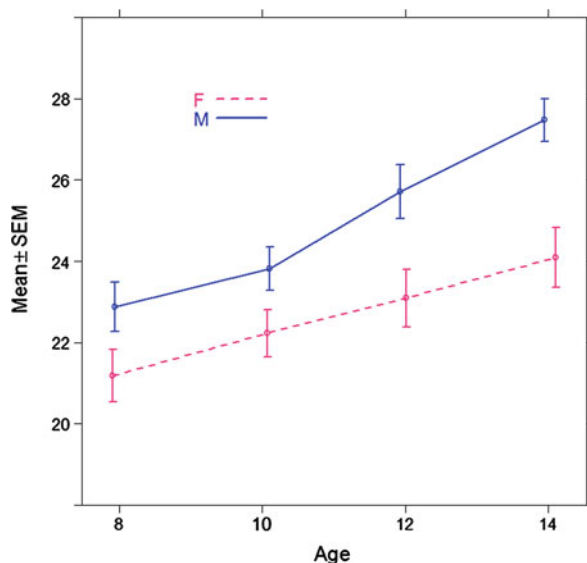


Fig. 4 Panel plots of boys' and girls' dental measurements (Potthoff and Roy 1964)

Fig. 5 Mean plots of dental observations \pm standard errors of the mean (SEM) by age and sex



In other cases, where the data are skewed, one can substitute medians for means, and say, the lowest and highest deciles for SEMs, and so on.

5 Fitting Appropriate Models to Repeated Measures Designs

In this section, I will discuss appropriate analyses for some classic repeated measures design.

5.1 Continuous Data

5.1.1 Analysis of Variance Approach

The simplest method of analyzing repeated measures data that is still used in some circles but has very limited utility is the “classical method” which is accomplished using analysis of variance (ANOVA) methods. Suppose that there are I cohorts or treatments in a repeated measures study and for each cohort, $i = 1, \dots, I$; there are n_i subjects, and there are T equally spaced observations per individual. A typical ANOVA model to analyze such a situation would be written as:

$$y_{ijt} = \mu_i + \gamma_{i(j)} + \tau_t + (\mu\tau)_{ik} + e_{ijt}, i = 1, \dots, I; j = 1, \dots, n_i; t = 1, \dots, T; \quad (1)$$

where y_{ijt} represents a measurement on subject j in cohort i at time t , $\gamma_{i(j)}$ represents a subject effect, τ_t represents a time effect, $(\mu\tau)_{ik}$ represents a potential time \times cohort interaction (moderation of cohort effect due to time), and e_{ijt} is the random error associated with measurement t on subject j within cohort i . This is referred to as a

Table 1 ANOVA table for the Potthoff and Roy data

Source	DF	SS	MSE	F-value	Prob > F
Sex	1	140.4649	140.4649	9.29 ^a	0.0054
Subject (Sex)	25	377.9148	15.1166	7.65	—
Time	3	237.1921	79.0640	40.03 ^b	<0.0001
Sex*Time	3	13.9925	4.66418	2.36 ^b	0.0781
Error	75	148.1278	1.97504	—	—
Total	107	917.6921	—	—	—

^aObtained by dividing the sex MSE by the Subject (Sex) MSE

^bObtained by dividing by the error MS

univariate model because the model is based on a single outcome as opposed to a “vector of outcomes” assumed by models developed later.

Here, the cohort and time effects are fixed, i.e., inference is limited to the prespecified levels used in a particular experiment. The “subject effect” is random, so that the subjects (patients, experimental units) in our experiment are assumed to represent a random sample from a large population. Hence, these types of models are known as *mixed effects* models. Furthermore, the subject effect itself can vary and so is associated with a probability distribution which assumed to be normal in the simplest case.

Specific to the ANOVA approach, the observations for each subject are assumed to form a *block* having the property that variability within blocks (i.e., within subject) is generally smaller than is the variability across subjects. In studies similar to that given our first example, the subject effect is said to be *nested within* the cohort effect and is denoted as such by the $\gamma_{i(j)}$ term. Hence, each subject is in one and only one cohort (can only be one sex in this case) or has one and only one treatment in treatment studies.

One trick that is used for both univariate and multivariate analyses seeking to fit polynomial trajectories is to transform the (equally spaced) time points into orthogonal coefficients. This is particularly useful as times t , t^2 , and t^3 tend to be highly correlated inducing correlation between corresponding coefficients. By orthogonalizing the coefficients, we can get uncorrelated estimates meaning that if, say, one wishes to reduce the degree of polynomial in a model and one or more coefficients are dropped, then the resulting coefficients will have the same values as in the original model, allowing one to make inference about each coefficient independent of all other coefficients. This property is not true for the coefficients of the original data. A more complete discussion of this topic is given in Hedeker and Gibbons (2006).

In Table 1, I fit such a univariate model to the dental measurement data. In this model, the cohort effect is due to sex (boys vs. girls).

Notice that F-test for sex is obtained by dividing the sex MS by the subject within Sex [denoted Subject (Sex)] MSE so that the F-test for comparing sexes has 1 and 25 DF. This is because each child is nested within gender (i.e., can be only one gender) so is considered a “block,” and hence the variation of interest for the denominator is associated with the subject (child) MS. The Time and Sex by Time effects, assuming

the correlations between repeated observations are the same across time, are tested via F-tests, both of which have 3 and 75 DF. Inference for uniformity of correlations across time points in this analysis indicates that the assumption of temporal uniformity of correlation structure for these data is reasonable.

The results indicate that we see highly significant growth in dental measurements in both sexes over time ($p < 0.0001$), but the average values of the dental measurements are significantly greater in boys than in girls ($p = 0.0054$). There is a nearly significant moderation ($p = 0.078$) in growth by sex indicating that the boys' average growth rate is higher but not significantly so than that of girls. An analysis (not shown) using orthogonal polynomials as described above indicate a significant linear growth effect in both boys and girls but the linear growth is significantly higher in boys than in girls. No significant quadratic or cubic growth terms were detected.

5.1.2 Multivariate Approach

Another way to handle nonuniform correlation structure is to model it using multivariate techniques. We can write a general multivariate model as $\mathbf{Y} = \mathbf{A} \mathbf{B} \mathbf{P} + \mathbf{E}$, where the rows of \mathbf{Y} represent the multiple observations of the subjects, the \mathbf{A} and \mathbf{P} are fixed matrices which allow one to test hypotheses between and within subjects, respectively, and \mathbf{E} is a matrix with rows that are each multinormally distributed and have the property that different rows are independent of each other (Rao 1958, 1965; Potthoff and Roy 1964; Grizzle and Allen 1969). To properly develop the covariance structure with these models, one has to *vectorize* the observations and change the other components of the model accordingly. As Potthoff and Roy (1964) pointed out in their paper, with the structure outlined above, one could test differences across sexes with the \mathbf{A} matrix and could fit a polynomial model for the subjects with the \mathbf{P} matrix.

Multivariate methods provide a big improvement over univariate methods in the modeling of repeated measures data in that they can address a broader set of questions and they allow a general structure to be modeled for the correlation structure in the errors. Hence, in most cases, such models are more efficient. However, they still are limited because:

- They don't allow subject effects to be easily distinguished and predicted.
- They don't handle unequally spaced data very well.
- They don't handle missing data well especially if there a lot of missing observations.

The mixed model regression approach discussed in Sect. 5.1.4 allows the analyst to easily address these problems.

5.1.3 Missing Data

As any investigator overseeing longitudinal studies knows, one of the greatest challenges during a study is to minimize missing information (Hedeker and Gibbons 2006; Fitzmaurice et al. 2009). In particular, one wishes to keep the number of subjects who completely drop out a study to a minimum.

There are three broad categories of missing data (Little and Rubin 2002). The first, called “missing completely at random (MCAR),” can be described as missing measurements that are not related to any other non-missing data nor are they related to latent variables or information that is not collected. This type of missingness is easily accounted for in modern mixed model analyses. The second broad category is called “missing at random” where the missingness can be accounted for by other *observed* measurements such as baseline demographics (age, race, clinical status) or previously observed measurements made longitudinally. As long as the proper observed covariates are accounted for in the analysis, this category poses no serious problem for modeling. The third category, known as missing not at random (MNAR), is when missing measurements are related to information not observed in the longitudinal study (e.g., future mortality status or characteristics not measured in a study) and can cause model inference to be biased.

5.1.4 Mixed Model Regression Approach

Modern methodology has focused on techniques that optimally model repeated measures data even in the presence of missing and/or unequally spaced observations made on each subject. These approaches explicitly model both the fixed and random effects associated with repeated measures data. The seminal papers by Harville (1977) and Laird and Ware (1982) were crucial in the development of these models. Consider the model given by:

$$y_i = \mathbf{X}_i\boldsymbol{\beta} + \mathbf{Z}_i\mathbf{b}_i + \mathbf{e}_i, \quad (2)$$

where y_i , $i = 1, \dots, n_i$, is a *vector of observations* for the i^{th} individual; \mathbf{X}_i and \mathbf{Z}_i are matrices that allow for cohort level and individual level covariate and time effects, respectively; $\boldsymbol{\beta}$ and \mathbf{b}_i are parameters that relate the cohort and individual effects to the outcome, respectively; and \mathbf{e}_i represents the random error *vector* for the i^{th} individual. For continuous data that is approximately normal or transformed to be approximately normal, the \mathbf{e}_i are $N(\mathbf{0}, \mathbf{R}_i)$, the \mathbf{b}_i are $N(\mathbf{0}, \mathbf{G}_i)$, and the correlation between the \mathbf{e}_i and the \mathbf{b}_i is assumed to be zero. The model given above accommodates both a population parameter vector, $\boldsymbol{\beta}$, (denoted without a subscript) which is common to all members of the defined population, and parameter vectors, \mathbf{b}_i , which are specific to each individual. The regression approach used in Eq. (2) allows time to be viewed and analyzed on a *continuum* as it should be rather than being a discrete (fixed) factor as in the ANOVA approach above. Thus, observation times need not be equally spaced to be properly analyzed using this approach. Furthermore, it allows one to model differing numbers of measurements on each individual. Hence, if there are missing values or the measurements being taken are inherently unequally spaced, the above approach can be employed with the caveat that the missingness is MCAR or MAR with appropriate covariates accounted for.

5.1.5 Properly Accounting for Correlation Structure

One challenge of fitting longitudinal models like that displayed in Eq. (2) is the fact that we must try to account for the variances and correlations among two sources of

random variation: (1) the coefficients of the random effects, b_i , which allow for individual trajectories to be fitted, and (2) the temporal correlation of the random errors. These estimates usually cannot be calculated in closed form so require optimization programs to maximize the likelihood function of the model. Hence, numerical algorithms must be implemented to approximate the optimal solutions. As the number of nonlinear parameters rises, the probability that solutions converge to a maximum goes down depending on the sample size and the nature of the data itself. For case (1), the number of random coefficients allowed for will determine the number of variance/covariance parameters. If, for example, there is only one random coefficient, then only the variance of that coefficient will require estimation. If, say, a random intercept and slope are to be estimated, then one must maximize the likelihood with respect to three parameters (the variance of each parameter and the covariance between them). For three random effects coefficients, six variance/covariance estimates must be made and any number of random coefficients beyond three usually results in models that do not properly converge.

With regard to properly accounting for the temporal structure in the errors, there are many possibilities, but three structures are the most common: independence in the error structure, uniform correlation over time, or a correlation structure that attenuates as time intervals between measurements increase. If the data are regularly spaced data, autoregressive [usually AR(1)] and Toeplitz structures are common. For irregularly spaced data, extensions known as continuous autoregressive (CAR) structures are often used (Jennrich and Schluter 1986; Jones and Ackerson 1990).

5.1.6 Motivating Example #2

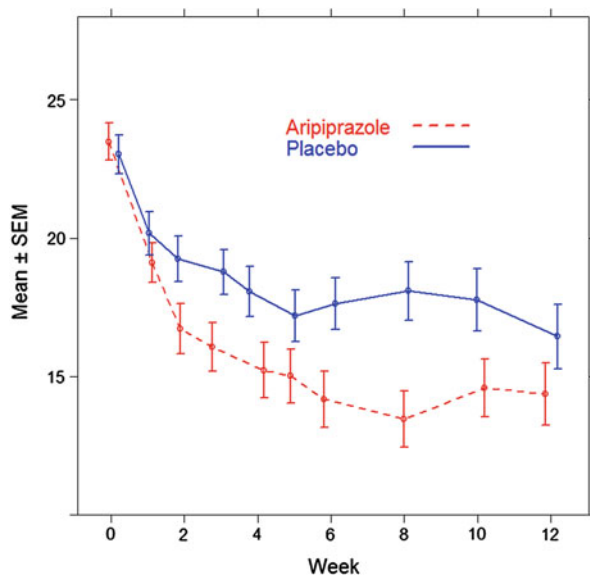
A recent study published in the *Lancet* (Lenze et al. 2015) involved a randomized comparison of Aripiprazole, a second-generation antipsychotic drug previously approved by the US Food and Drug Administration for augmentation treatment of major depressive disorder with a placebo. In the study, 468 eligible participants were recruited at three sites; 181 did not remit and were randomly assigned to aripiprazole ($n = 91$) or placebo ($n = 90$). A greater proportion of participants in the aripiprazole group achieved remission than did those in the placebo group participants (44% vs. 29%; odds ratio [OR] 2.0 [95% CI 1.1–3.7], $p = 0.03$). One of the primary endpoints in the study was the Montgomery-Asberg Depression Rating Scale [MADRS]. For the MADRS endpoint, a lower score is better, and a remission was defined as a MADRS score of 10 or less. The data were reasonably normally distributed. Summary statistics are given in Table 2, and mean values plus or minus standard errors (SEM) are plotted by treatment and time point (Fig. 6). Note that there was attrition in both groups as the sample sizes reduced from 91 to 68 in the aripiprazole group and from 90 to 71 in the placebo group. The best fitting trajectories were cubic polynomials, and an overall reduction in the trajectory of the MADRS scores was observed for the aripiprazole group, indicating that the drug was associated with less depressive symptoms (Table 3). Note that, even though some of the differences between the groups in the terms of the cubic polynomials were not significant, the overall difference in the polynomials was significant (overall time \times treatment p -value ≈ 0.017). A plot of the trajectories as predicted by the model is displayed in Fig. 7.

Table 2 MADRS data: means and standard deviations by week and treatment group

Trt ^a	Arip	Arip	Arip	Arip	Arip	Arip	Arip	Arip	Arip	Arip
Week	0	1	2	3	4	5	6	8	10	12
Mean	23.47	19.11	16.73	16.06	15.22	15.01	14.18	13.47	14.58	14.37
Std dev	6.43	6.64	8.4	8.2	9.27	8.89	9.03	8.75	9.3	9.34
N	91	89	88	87	86	84	79	75	79	68
Trt ^a	Plac	Plac	Plac	Plac	Plac	Plac	Plac	Plac	Plac	Plac
Week	0	1	2	3	4	5	6	8	10	12
Mean	23.02	20.17	19.26	18.78	18.07	17.18	17.64	18.08	17.77	16.44
Std dev	6.58	7.53	7.79	7.46	8.34	8.41	8.54	9.09	9.65	9.93
N	90	90	90	85	86	82	85	73	74	71

^aArip Aripiprazole, Plac Placebo

Fig. 6 IRL-Grey mean MADRS data standard errors of the mean (SEM) plotted by weeks rounded to the expected visit times by treatment group



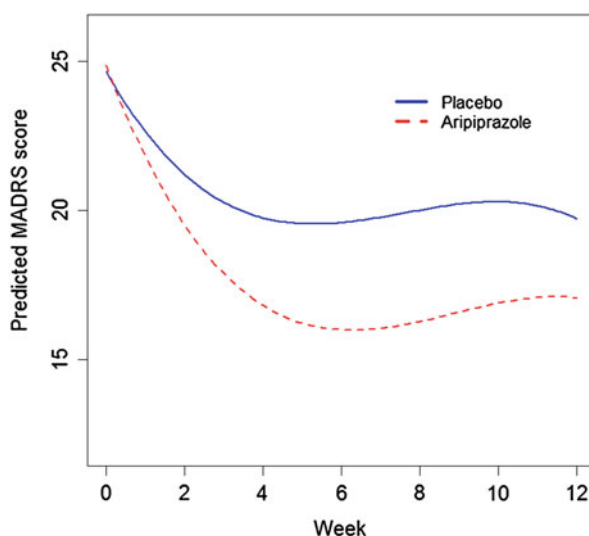
5.2 Models for Binary and Other Discrete Data

In some cases, a variable measured repeatedly on one or more cohorts may be of a binary or, more generally, discrete nature. This is often encountered in the social sciences where simple distinctions, such as one feeling distressed or not or functioning better or worse or cognitive ability decreasing or not, are studied over time (Muenz and Rubinstein 1985; Zeger and Liang 1986). Two primary approaches are used for the analysis of such measurements in a longitudinal study.

Table 3 Type III fixed effects statistics for the aripiprazole study

Source	Num. DF	F-value	Prob > F
Age at entry	1	12.82	0.0004
Site	2	6.59	0.0014
Intercept	1	0.04	0.84
Linear	1	136.63	< 0.0001
Quadratic	1	72.49	< 0.0001
Cubic	1	44.36	< 0.0001
Treatment*TIME	3	–	0.017^a
Treatment*linear	1	4.99	0.026
Treatment*quadratic	1	0.93	0.33
Treatment*cubic	1	0.06	0.80

^aCalculated using a likelihood ratio test

Fig. 7 IRL-Grey-2 predicted MADRS scores for typical participants

5.2.1 Marginal Models

Here, I present the seminal work by McCulloch and Nelder (1982, 1989) in the development of *generalized* linear models. Their approach involves “link functions,” g , given by:

$$g(\mu) = g(\mathbf{X}_i\boldsymbol{\alpha})$$

where \mathbf{X}_i is a matrix with columns containing each individual’s (denoted with a subscript i) measurements (covariates) and $\boldsymbol{\alpha}$ is a parameter to be estimated that relates the covariates to the transformed outcomes and hence the mean response, $\mu = \mathbf{X}_i\boldsymbol{\alpha}$. Typical link functions include the logit and exponential functions for binary (e.g., yes/no, event/no event) outcomes.

The generalized linear model framework was adapted to fit longitudinal data by the groundbreaking work of Liang and Zeger and others at the Johns Hopkins University (Liang and Zeger 1986; Zeger and Liang 1986). They used “generalized estimating equations” that allowed them to first fit marginal longitudinal data assuming a “working covariance structure” that initially assumed independence and then tried to correctly model the within subject covariance structure.

Using this GEE approach, one can easily handle binary, discrete, or even continuous measurements in a general framework allowing for MCAR or MAR missingness and appropriately accounting for other covariates and repeated outcomes to be modeled. Excellent references for this method are given in Hardin and Hilbe (2003), Brown and Prescott (2006), and Diggle et al. (2002).

5.2.2 Transition Models

Another approach to modeling binary and general discrete outcomes measured repeatedly is done by characterizing the probabilities of transitioning from different binary or discrete “states,” for example, the probability of going from “feeling good” to “feeling bad” or vice versa. These models can be adapted to adjust for covariates. Good references for this type of model can be found in Muenz and Rubinstein (1985), Molenberghs and Verbeke (2005), and Diggle et al. (2002).

6 Discussion and Future Directions

The purpose of this chapter was to familiarize the reader with the design and analysis of different types of longitudinal studies. Longitudinal study designs allow researchers to investigate trajectories of phenomena of one or more populations over short- or long-term periods of time (or both). Analysis techniques allow one to make inference both at the individual and population levels. Due to the temporal nature of these studies, causal relationships of interventions on outcomes can often be established particularly when the study involves randomization of the participants into different intervention groups.

The field of longitudinal data analysis has exploded in the last 50 years with different methods. As is noted by many authors (Ware 1985; Rizopoulos 2012), most longitudinal studies collect both follow-up (time-to-event or survival) data along with data that is measured repeatedly. Accordingly, in recent years, a common goal of longitudinal studies is to relate a set of repeated observations to a time-to-event endpoint (Henderson et al. 2000; Song et al. 2002; Guo and Carlin 2004; Rizopoulos 2011, 2012). One example of such a design is in the area of late-life depression research where repeated measurements of cognitive and functional outcomes can contribute to one’s ability to predict whether or not an individual will have a relapse of a major depressive episode over a period of time (Reynolds et al. 2011).

Another area of recent research is that of modeling *intensive* longitudinal data (Wallis and Schafer 2006). This field has arisen due to our ability to measure hundreds or thousands of measurements on each subject within a set of cohorts in a longitudinal study and how to account for complex within subject variation while,

at the same time, making inference on a cohort level for possibly complicated patterns (e.g., circadian, daily and yearly patterns seen in an overall cohort or set of cohorts). Two examples of such studies are cardiac monitoring and exercise monitoring studies where thousands of typically equally spaced measurements are made per individual. A third is monitoring behavioral or physical activity based on random “prompts” from an electronic diary leading to large numbers of observations that are usually not equally spaced in a single individual and may occur at varying time points over a cohort of individuals (Stone et al. 2007; Shiffman et al. 2015).

Another area of recent research for longitudinal data analysis is that of so-called “latent class” trajectory models (Nagin 1999; Roeder et al. 2011). The primary focus of such studies is to identify classes of trajectories of different subsets of a cohort based on the trajectories themselves and a set of covariate levels that are unique to each subset. These methods are best suited to observational studies or as hypothesis-generating studies in randomized trials.

Because real-time data acquisition continues to get more sophisticated, the future challenges of designing and analyzing longitudinal studies to accommodate such advances will be formidable. For example, data acquisition systems now allow us to measure high-dimensional data such as genomic or imaging data over time. This type of information typically involves data with more variables than there are subjects (Hastie et al. 2009; Zipunnikov et al. 2014; Chen and Lei 2015) and requires appropriate dimension reduction techniques to properly fit models. To design and model studies that allow scientists to accurately model such data, along with other traditional demographic and clinical information measured cross-sectionally and repeatedly, will be a great challenge. Furthermore, relating these measurements to ultimate events such as relapse and mortality will occupy much future research at statistical and, more generally, scientific levels. Lastly, many times, several repeated measurements are made simultaneously, and sometimes it is appropriate to model such processes jointly by themselves or as predictors of time-to-event outcomes. Methods for doing so are another area of ongoing research (Choi et al. 2014).

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Eliciting Preferences from Choices: Discrete Choice Experiments 36

Martin Howell and Kirsten Howard

Contents

1	Introduction	624
2	What Are Preferences?	625
3	Estimating Preferences from Choices	627
3.1	Theoretical Framework for Discrete Choice Experiments	628
3.2	Best–Worst Scaling Surveys	631
4	Steps to Conducting a Discrete Choice Experiment	635
5	Conclusions and Future Directions	640
	References	641

Abstract

Discrete choice experiments (DCEs) have been widely used as a research tool to elicit the preferences of patients, clinicians, the community, and policy-makers for a range of health-related questions including complex interventions, treatment options, health programs (e.g., cancer screening) and policies, and health service delivery. In a DCE, treatments or health programs are described by a set of attributes with varying levels, for example, health outcomes (harms and benefits), cost, time, properties of the procedure (e.g., injection or tablet), and so on. The participant is asked to choose their preferred treatment or program. By systematically varying the attribute levels across a range of choices, preferences for health goods and services can be calculated. Unlike other preference elicitation techniques such as ranking or rating, DCEs are underpinned by a well-established and robust theoretical framework that allows estimation of a range of outputs, including the relative importance of individual attributes within a multi-attribute health

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623

program (e.g., waiting time, travel time, type of care), the trade-offs individuals may be willing to accept between attributes (e.g., side effects and survival), as well as willingness to pay and uptake of health programs. This chapter provides an overview of the theory and application of DCEs.

Keywords

Discrete choice experiments · Best-worst scaling surveys · Preference elicitation · Preferences and values

1 Introduction

It is increasingly recognized that health interventions/programs, research priorities, policies, and resource allocation should reflect the values, preferences, and priorities of patients, their carers, and the community. Individuals and societies value additional outcomes of health care beyond just clinical outcomes. Indeed, if the long-term benefits and harms are unclear or there are multiple options with differing outcomes including undesirable side effect profiles and serious adverse outcomes, then patient's values, preferences, and priorities for these other outcomes may be as important to decisions as medical factors (Braddock 2013). Issues for patients and their carers extend beyond medical considerations and include a range of social and financial factors all of which may change before, after, and during the course of a health intervention (Martin et al. 2010). Similarly, the relative importance of medical factors may change over the course of treatment, particularly with chronic or incurable conditions, the development of comorbidities, and adverse outcomes. Disparate medical and nonmedical factors may contribute to decisional conflicts arising from the changing need to balance benefits and harms and the potential discord with values, preferences, and priorities (Murray et al. 2009; Mühlbacher and Juhnke 2013). Allocation of finite resources for health-care programs requires a balance between making the best use of a finite resource (efficiency) and being fair (equity). There are four key principles underpinning this balance, which have been reflected in community preferences and priorities, namely, "treating people equally," "favoring the worst off," "maximizing benefits," and "promoting social usefulness" (Persad et al. 2009). Finally, individual preferences are key to assigning a utility weight (Quality Adjusted Life Year weight) to health states used in economic evaluations of health interventions and programs (Richardson and Manca 2004).

Preferences can be measured using a variety of qualitative and quantitative approaches. The most commonly used methods include focus groups, structured interviews, mixed methods such as the nominal group technique, surveys with or without rating and ranking scales, standard gamble and time trade-off (Torrance 1986), and discrete choice experiments (DCEs) (see ► Chaps. 23, "Qualitative Interviewing," ► 40, "The Use of Mixed Methods in Research," ► 42, "Consensus Methods: Nominal Group Technique," and ► 32, "Traditional Survey and Questionnaire Platforms").

Discrete choice experiments have been applied to a wide range of health-related questions at a patient, clinical, community, and policy level. These have included eliciting patient, clinician, and community preferences and priorities for outcomes of interventions, treatment options, and a range of health programs such as cancer screening and health service delivery (de Bekker-Grob et al. 2012; Clark et al. 2014; von Arx and Kjær 2014; Wortley et al. 2014) as well as eliciting utility weights for health states (Ratcliffe et al. 2009, 2011; Norman et al. 2013; Viney et al. 2014). One main advantage of DCEs over other approaches such as ratings, rankings, standard gamble, and time trade-off is that they enable assessment of priorities and preferences beyond the simple ordinal scales of these other techniques. Furthermore, trade-offs between desirable and undesirable outcomes, the willingness to pay for services, and estimation of uptake of community wide programs can also be evaluated (Chuck et al. 2009; Regier et al. 2009; Groothuis-Oudshoorn et al. 2014; Howard et al. 2014; Kawata et al. 2014; Laba et al. 2015; Kan et al. 2016).

This chapter provides an overview of discrete choice experiments (DCEs) that have, since the 1990s, become one of the most commonly used quantitative techniques for eliciting preferences and priorities in health-related research questions.

2 What Are Preferences?

Before describing DCEs, it is necessary to understand what is meant by preferences. In health research, despite the terms patient, consumer, community, or individual preferences or values being widely used, there is no clear definition or understanding of either preference or values (Street et al. 2012). Individual “values” have been used interchangeably with preferences, or preferences are seen as a subset of “values” and vice versa. Patient preferences have also been defined as being the final choice or decision in the context of shared decisions (Brennan and Strombom 1998). The Institute of Medicine defines patient values as referring “to the unique preferences, concerns, and expectations that are brought by each patient to a clinical encounter [that] must be integrated into clinical decisions if the patient is to be served” (Committee on Quality of Health Care in America Institute of Medicine 2012, p. 47). Under this definition, “preferences and concerns” is a broad concept and implicitly includes cultural identity, existential and nonexistential beliefs, and personality traits such as aversion to risk (Koltko-Rivera 2004; Daher 2012) as well as treatment-related factors (Blinman et al. 2012). In the context of health, it is more useful to think of values and preferences as separate concepts. Values reflect an individual’s identity and world view (Koltko-Rivera 2004), while preferences reflect an individual’s evaluation of benefits, harms, costs, and inconveniences of one treatment option compared to another (Blinman et al. 2012) at a particular point in time. This distinction is important. Preferences are underpinned by beliefs about the consequences of outcomes and anticipation of the ability to cope or adjust (Blinman et al. 2012), while “values” largely reflect cultural, social, and other influences not directly related to the intervention (Koltko-Rivera 2004; Daher 2012). For complex questions or decisions, knowledge and experience have a strong influence on an

individual's beliefs of the consequence of an outcome. This could include expectations of improvement or deterioration to quality of life, anticipation of the range and severity of side effects, and the range and likelihood of adverse outcomes associated with an intervention. Expectations are in turn strongly influenced by interactions with health professionals, other patients, family, friends, and the media (Ubel et al. 2005; Epstein and Peters 2009; Hausman 2012; Dirksen et al. 2013).

A prime distinction between “preferences” and “values” is that as expectations and beliefs change with time, experience, and health (Ubel et al. 2005), “preferences” for treatment options may vary or even reverse (Slovic 1995). This is particularly so with chronic health conditions (Dipchand 2012; Gordon et al. 2013). Indeed, for complex problems or where there is no clear choice, preferences may be constructed during the decision process (Slovic 1995). In contrast, individual values are influenced by cultural and societal norms, religious and nonreligious beliefs, and close relationships (family and friends). Thus more stable aspects of an individual's “world view” define values (Koltko-Rivera 2004; Daher 2012). Furthermore, preferences may be underpinned by beliefs and expectations that are erroneous or biased (skewed). Moreover, there may be little or no relevant experience to draw on to formulate well-founded beliefs and expectations (Hausman 2012). In contrast to values, erroneous or skewed beliefs of consequences may be challenged and influenced by health professionals (Légaré et al. 2012).

In summary, patient preferences are best defined as “statements made by individuals regarding the relative desirability of a range of health experiences, treatment options and health statements” (Brennan and Strombom 1998, p. 259). An individual's preference for a treatment “reflects their evaluation of its relative benefits, harms, costs, and inconveniences in comparison with a given alternative or alternatives” (Blinman et al. 2012, p. 1104). The goal of patient-centered care or shared decision-making should be that patient preferences are well informed and lead to patient decisions that are ultimately aligned with their values.

Broadly speaking, there are two types of preferences, revealed and stated:

- Revealed preferences are inferred by what people actually choose when presented with alternatives, for example, choosing whether to purchase private health insurance or participate in a cancer screening program.
- Stated preferences are inferred from what an individual says they would do given a hypothetical choice. They can be used to predict future choices or identify the attributes of an intervention or program such as the risk of adverse outcomes that most influence their choices. Stated preferences are also used to assign values to health states and health goods and services (Lancsar et al. 2011).

In health-care settings, revealed preferences are difficult to uncover, and the choices made commonly do not reflect the preferences of the person accessing a service or choosing an intervention. Available options are commonly constrained by structural barriers to access, and the preferred alternative may not be available, for example, rural and remote patients may have limited access compared to urban settings. Furthermore, as physicians act as the gatekeepers to many if not most health

services, the choice made may reflect the physicians' preferences and not their patients. Also different physicians may offer access to different options even within a single health-care setting. In contrast, the stated preference for an intervention or health state reflects a personal evaluation of what it would be like to live with one set of outcomes or conditions compared to another set. In addition, health research is commonly interested in understanding factors that might influence acceptance (or not) of public health programs or treatment options (Lancsar and Louviere 2008; de Bekker-Grob et al. 2012; Clark et al. 2014) to assist in development of the programs. As a consequence, studies in health mostly address stated rather than revealed preferences.

An important limitation common to all methods of preference elicitation including DCEs is that individual preferences are underpinned by expectations and beliefs that are in turn influenced by the way in which outcomes or services are framed or communicated. In short, stated preferences may be a construct of the elicitation method (Slovic 1995). As such, "data from preference elicitation tasks partly reflect individuals' preferences and partly the manner in which the preferences were elicited" (Lloyd 2003, p. 394).

3 Estimating Preferences from Choices

Discrete choice experiments (DCEs) have become one of the most common techniques to elicit preferences in situations where choosing a commodity (or a health program, intervention, service, and so on) is dependent on multiple aspects or attributes of that commodity. As a simple illustration, when choosing to drive or catch a bus to work, an individual will take into account multiple factors such as the cost, convenience, travel time, availability of parking, and weather. Furthermore, if one or more of these factors change, for example, the weather goes from sunny to rainy, their decision may switch from the bus to the car. A DCE can elicit preferences for the multiple attributes, and these can be used to predict when and how often the bus might be chosen or to develop strategies that encourage greater use of the bus. The advantage of a DCE over simple ranking or rating scales is that behavioral factors underpinning preferences can also be evaluated (Train 2009). There are three broad areas where DCEs have been particularly useful in health-related research:

1. Identifying individual preferences, priorities, and values for health service delivery, health prevention programs, treatment options, etc. and outcomes and preferences for specific health states.
2. Evaluating the trade-offs individuals may be willing to make in balancing benefits and harms. For example, the trade-off between treatment-related side effects and adverse outcomes and disease-free survival.
3. The trade-off individuals may be willing to make to achieve a desirable outcome or avoid an undesirable outcome. This could be in terms of trading the length of life for a shorter but better quality of life or willingness to pay more to attend a clinic with shorter waiting times or to receive an alternate treatment.

3.1 Theoretical Framework for Discrete Choice Experiments

Discrete choice experiments derive preferences by analysis of choice data that has been collected in a systematic way. In a DCE, individuals are asked to make a series of hypothetical choices between two or more options where the options are described by a defined set of attributes. By systematically varying the values of the attributes across multiple choices, the relative preferences for each attribute can be estimated (Bryan and Dolan 2004). Attribute values may be descriptive, ordinal, continuous, or categorical. Figure 1 shows a single choice task for a UK study of preferences for local neighborhood physician practices versus those out of the local area (Lagarde et al. 2015). The attributes characterizing the clinics are flexibility of opening hours; time taken to get an appointment, whether the clinic meets individual health needs; and the experience of the clinic. In this study, participants were shown 16 separate choice tasks across which the values of the attributes have been systematically varied.

The analysis of the choices made in a DCE such as shown in Fig. 1 is underpinned by a theoretical framework of choice behavior and utility maximization proposed and largely developed by econometricians (For an overview of the history of development of choice modeling, refer to Hensher et al. 2016) and applicable to all of the many disciplines in which DCEs have been used (Hensher et al. 2016). This choice theory assumes that when an individual decides between the two clinics, the choice of one over the other is based on a collective assessment of the attributes. The

Question 1 of 16	Practice in your local neighbourhood	Practice outside your local neighbourhood
Open Saturday and Sunday morning	Not open	Open
Open at lunchtime	Always	Sometimes
Extended opening hours	No extended hours	Extended hours
How quickly can usually see a GP	Normally in the next few days	Normally same day
Meets your specific health needs	Yes	Yes
How well the practice knows the health care services	The practice has experience with most providers	The practice has experience with some providers
Which would you choose to register with?	<input type="radio"/>	<input type="radio"/>

Fig. 1 A single scenario for the choice of a primary care clinic has been adapted from a discrete choice experiment to elicit preferences for GP practices in the UK (Lagarde et al. 2015). The clinics options are described by 6 attributes the values of which are varied across 16 choice scenarios

clinic with the most favorable balance of attributes will be chosen as this maximizes the individual's satisfaction or utility (Hensher et al. 2016). A change in just one attribute, say being open on a Saturday, could result in a switch in choice from one clinic to another. This choice theory is known as random utility maximization or random utility theory (RUT) (McFadden 2001) and has been applied across many economic and noneconomic disciplines including marketing, transport, environmental economics, and health-related research (Clark et al. 2014). Random utility theory underpins both the design and analysis (Hensher et al. 2005; Lancsar and Louviere 2008) of DCEs across all of these fields.

The "random" component in RUT arises from the researcher's inability to identify every single attribute that characterizes the options or to know all of the individual's characteristics that influence their choice. As a consequence, an individual's choice may reflect attributes and characteristics not known to the researcher and, therefore, not included in the DCE. These may be totally unrelated to the included attributes, or an unknown factor may be substituted for one of the defined attributes. In the example shown in Fig. 1, an individual may prefer out of area clinics as they may think local clinics to be more likely staffed by local residents and to present privacy concerns for them. This would be unrelated to the included attributes. In contrast, if an individual had an underlying (latent) preference for smaller clinics, they may consider that extended opening hours are likely to suggest a large busy clinic rather than a small one. In this case, extended opening hours could be substituted for the suspected size of the clinic, and this then influences their choice. The choices made in the DCE are also influenced by errors of judgment arising from the lack of knowledge of the meaning or the consequences of an attribute or option, poorly described or ambiguous attributes, and a range of survey completion errors. Random utility theory recognizes all of these as contributing to a random component of utility. The utility associated with a choice can then be expressed as the sum of the utility associated with known factors and the unexplainable random component (Lancsar and Louviere 2008; Hensher et al. 2016):

$$U_{(ij)} = V_{(ij)} + \varepsilon_{(ij)} \quad , j = 1, \dots, J$$

Where:

$U_{(ij)}$ is the utility for individual i for choice j
 $V_{(ij)}$ is the explainable component as defined by the attributes and characteristics, and
 ε_{ij} is the unexplained or random component of utility.

The explainable component of utility is generally considered to be a linear function of the properties of the attributes and known characteristics of the participants such as age, gender, and health according to the following equation (Lancsar and Louviere 2008; Hensher et al. 2016):

$$V_{(ij)} = X_{(ij)}\beta + Z_{(ij)}\gamma$$

Where:

$X_{(ij)}$ is the vector of attributes included in the design,

$Z_{(ij)}$ is the vector of participant characteristics or other covariate, and

β and γ are the vector coefficients to be estimated.

In the example shown in Figure, 1 the utility functions for the local and non-local clinics can be written as:

$$V_{\text{local}} = ASC_{\text{local}} + \beta_{\text{sat_sun}} * \text{sat_sun} + \beta_{\text{lunchtime}} * \text{lunchtime} + \beta_{\text{extended}} * \text{extended} \\ + \beta_{\text{time_GP}} * \text{time_GP} + \beta_{\text{health_needs}} * \text{health_needs} + \beta_{\text{experience}} \\ * \text{experience}$$

$$V_{\text{non-local}} = ASC_{\text{non_local}} + \beta_{\text{sat_sun}} * \text{sat_sun} + \beta_{\text{lunchtime}} * \text{lunchtime} + \beta_{\text{extended}} \\ * \text{extended} + \beta_{\text{time_GP}} * \text{time_GP} + \beta_{\text{health_needs}} * \text{health_needs} \\ + \beta_{\text{experience}} * \text{experience}$$

Where:

ASC_{local} and $ASC_{\text{non_local}}$ are alternative specific constants for the two types of clinics.

$\beta_{\text{sat_sun}}$, $\beta_{\text{lunchtime}}$, etc. are regression coefficients for the attributes
sat_sun, lunchtime, etc. are the attribute values.

Alternative specific constants provide some information on the unobserved effects; in this case, it would indicate if there was an underlying (latent) preference for one clinic over another irrespective of the known attributes. One approach that can be used to minimize the effects of a latent preference and to encourage greater consideration of the individual attributes is not to label the clinics and simply call them A and B. Including a choice option of “I would choose neither clinic” can also encourage greater consideration of the individual attributes.

Estimation of coefficients in the utility function is undertaken using regression models that apply varying assumptions to account for the random error component ϵ_{ij} (Readers are referred to the following texts for detailed descriptions of the derivation of regression models for choice analysis: Train (2009); Hensher et al. (2016)). The simplest approach assumes that ϵ_{ij} is independent of and identically distributed across all participants that allows a closed-form computation of a multinomial logit (MNL) regression model. Essentially, this simplification assumes that the unknown portion of utility of one alternative is unrelated and independent of all other alternatives in the DCE. Furthermore, it assumes that each choice is an independent observation, which is not the case as individuals provide multiple choices or observations and these are unlikely to be independent. This greatly

simplifies the estimation of the utility function and enables estimation of average preferences across populations. However, it presents limitations in the evaluation of heterogeneity of preferences between individuals and correlation of preferences within individuals (Train 2009). For example, in the UK study shown in Fig. 1, individuals who were 65 years and older and those who look after their family at home (both known characteristics) were more likely to choose the local practice. This preference could reflect distinct and essentially independent unobserved reasons, for example, the lack of access to transport for the elderly and the desire to minimize time away from home for the second group. Alternatively, the reasons could be related or even the same, as the elderly may have to rely on the same family carers for transport. Under the simplifying assumption of an MNL, it is not possible to evaluate these associations. Despite these shortcomings, Train (2009) makes the point that in many situations, the MNL provides a simple and robust approach to the evaluation of preferences and is often sufficient to provide good estimates of average preferences (Train 2009).

A number of approaches have been developed to relax the simplifying assumptions of the MNL. These include forms of MNL models that use simulation methods to allow for heterogeneity within and between individuals with respect to known and unknown factors and to allow for correlations between choices made by individual participants. These mixed or random component MNLs also allow estimation of individual as well as average preferences. Other approaches include latent class and nested MNL models that allow for heterogeneity between the classes or nests while enforcing the simplifying MNL assumptions within the classes/nests (Lancsar and Louviere 2008; Hensher et al. 2016). Table 1, adapted from Hauber et al. (2016), provides a summary of commonly used approaches to DCE estimation methods and advantages and limitations.

3.2 Best–Worst Scaling Surveys

A best-worst scaling (BWS) survey is a specific form of DCE that was initially developed as a means of increasing the information obtained from a DCE by providing partial or complete rankings of choice options rather than a single choice (Flynn et al. 2007). In a BWS, the participant is asked to indicate the most preferred or best option and also the least preferred or worst option. Depending on the number of options, participants could be asked to indicate the best, worst, next best, next worst, and so on. There are three broad types of BWS surveys (Louviere et al. 2015), and these are briefly described below.

Object scaling (Case 1). These are suited to eliciting preferences for a large list of factors or objects. Rather than asking participants to rank all of the factors from least to most important, they are shown a small subset and asked to choose the best and the worst (most important, least important) from that subset. They are shown multiple subsets where the factors presented are varied and the best and the worst is chosen for each subset. Analysis of the choices provides a basis for identifying the relative

Table 1 Advantages and disadvantages of common analysis methods (Adapted from Hauber et al. 2016)

Method	Advantages	Limitations
Multinomial logit (MNL)	Focuses on average preferences Commonly available in software packages	Assumes homogeneity in preferences. Does not account for correlation of choices made by individual participants.
Random-parameters logit or mixed MNL	Models heterogeneity. Accounts for the panel nature of the data. Available in some software packages. Can deal with heterogeneity of preferences and allow for correlation across attributes	More difficult to use than MNL. Requires assumptions about the distribution of parameters across respondents. Requires larger sample sizes than MNL models
Latent-class model	Models latent classes and describes heterogeneity by class. Requires smaller samples than mixed MNL and RPL	Requires specialized software. Judgment required to determine appropriate number of classes. Difficult to interpret results from any given class when the chance of being in all classes is more or less the same across respondents. The required sample size varies with the number of classes in the model

Identify which technology you believe will have the most impact and the least impact in your country over the next 5 to 10 years		
	Most impact (one only)	Least impact (one only)
Molecular target therapy	<input type="checkbox"/>	<input type="checkbox"/>
Stem cell therapy	<input type="checkbox"/>	<input type="checkbox"/>
Adjuvant/Neo-adjuvant therapies	<input type="checkbox"/>	<input type="checkbox"/>
Transplant technologies	<input type="checkbox"/>	<input type="checkbox"/>
Genetic/Genomic biomarkers	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 2 Example of an object scaling (Case 1) BWS. Adapted from a survey of clinicians regarding their expectations of the impact of 11 emerging technologies for the treatment of hepatocellular carcinoma (Gallego et al. 2012). Participants were shown a series of choice sets each with a different subset of the five technologies

importance of all of the factors on a continuous scale. An example of an object scaling BWS is shown in Fig. 2.

Profile scaling (Case 2). These are applied where a single profile (e.g., a health state, treatment, or service) can be described by a set of attributes that can have varying values or levels. Multiple scenarios of single profiles are shown to participants all of which have the same attributes; however the values of the attributes are varied between scenarios. As for the Case 1, BWS participants are asked to select the best and worst attributes from the profile. The attribute levels may be numeric (the

Consider the following attributes in asthma control. Which do you consider to be the best and which is the worst.		
Best		Worst
<input type="checkbox"/>	Night symptoms: 3 days per week	<input type="checkbox"/>
<input type="checkbox"/>	Wheezing or tightening of the chest: None	<input type="checkbox"/>
<input type="checkbox"/>	Changing medication: To add oral steroids for 5 days	<input type="checkbox"/>
<input type="checkbox"/>	Emergency visits: 10 per year	<input type="checkbox"/>
<input type="checkbox"/>	Limitation to physical activities: 2 times per month	<input type="checkbox"/>

Fig. 3 Example of a profile scaling BWS (Case 2). Adapted from a study eliciting preferences of parents and adolescents for the control of asthma (Ungar et al. 2014). Each attribute is described by 3 to 4 levels representing the range of possibilities for that attribute (e.g., nighttime symptoms, none, 3 days a week, 5 days a week). Each choice set contains the same five attributes; however the attribute levels are varied across the choice sets

probability that a side effect will occur) or descriptive (the severity of the side effect). It has been suggested that when there are a large number of attributes, the Case 2 BWS survey is less cognitively demanding than a DCE and that it should result in greater consideration of all attributes (Flynn et al. 2007), although this view is not universally accepted (Whitty et al. 2014a, 2014b). An example of a profile scaling BWS is shown in Fig. 3.

Best-worst DCE (Case 3). The best-worst DCE is essentially a standard DCE that includes an additional best-worst task. Each scenario consists of three or more multi-attribute profiles as per a DCE, and participants are asked to show their preferred option and then to select the worst of the remaining profiles (Lancsar et al. 2013). Case 3 aims at augmenting data collected from the DCE by providing partial or complete ranking in addition to the preferred choice. An example of a best-worst DCE is shown in Fig. 4.

Since 2008, BWS surveys have gained increasing use in the evaluation of health-related research questions; however, the absolute number has been relatively small with 53 publications overall and only 15 and 16 published in 2014 and 2015, respectively (Mühlbacher et al. 2016). They can be cognitively less demanding than DCEs, although as noted above, this is not universally accepted (Whitty et al. 2014a, 2014b), and enable assessment of the relative importance of a large number of attributes on a continuous scale avoiding issues associated with ranking and rating techniques. Compared to DCEs, a BWS can provide a more realistic approximation of questions where there is no clear choice to be made. For example, maintenance immunosuppression after transplantation is best described as a series of adjustments with resulting changes to the benefits and harms rather than a discrete choice of one option over another. Another advantage is that attributes are assessed on the same underlying scale, enabling direct comparison of the relative importance of attribute

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
Arm/hand function	Normal	Impaired	Impaired	Impaired
Walking	Wheelchair	Normal	Wheelchair	Wheelchair
Bladder Bowel	Impaired	Impaired	Normal	Impaired
Sexual	Normal	Dysfunction	Dysfunction	Dysfunction
Pain	Occasional	Occasional	Occasional	Persistent
Best	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Second best	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 4 Example of a best-worst DCE task. Adapted from a study of people with a spinal cord injury (Lo et al. 2016). Each attribute is described by two levels representing possible outcomes for that attribute (e.g., walking; wheelchair or normal). In each choice set, the attributes remain the same; however the attribute levels are varied across the choice sets. In this example, participants are asked to select the best (i.e., their choice in the DCE as well as the worst scenario and their second best scenario)

levels both within and between attributes (Marley et al. 2008; Flynn 2010; Louviere et al. 2015).

As BWS surveys are underpinned by the same random utility framework as DCEs, design and analysis follow the same general principles (Marley et al. 2008; Louviere et al. 2015; Mühlbacher et al. 2016). At the simplest level, the best and worst choices can be counted for each attribute level with the best minus the worst score providing a measure of the preference for the attribute levels. While this has been shown to provide a robust estimate of relative importance, it does not allow for estimation of trade-offs between attributes (Louviere et al. 2015).

When using MNL models, there are considerations specific to the completion of a BWS survey that need to be taken into account. The most important are assumptions as to the order in which selections are made, for example, the best first then the worst, or the other way around or both at the same time, and in terms of utility whether a worst selection is a negative mirror of a best. Completion styles may vary between participants, and the magnitude and direction between desirable and undesirable attributes may vary between participants and attributes (Rose 2014). In Louviere and Flynn's view, as the differences are most likely minor, the pragmatic approach is to simplify analysis by assuming the worst is a negative mirror of and selected after the best choice (Louviere et al. 2015).

In summary, a BWS survey is an alternate approach to eliciting preferences under the general framework of random utility theory. They have potential advantages to DCEs including ability to assess attributes and attribute levels on the same underlying scale and to avoid problems associated with rating and ranking techniques. A BWS survey can be used as a data augmentation technique for a DCE or as an alternate solution to elicitation of patient preferences for multiple attributes associated with complex health questions.

4 Steps to Conducting a Discrete Choice Experiment

Comparative studies of preference elicitation techniques suggest that DCEs (and BWS surveys) encourage greater consideration of all attributes and should provide more thorough evaluations of complex questions (Pignone et al. 2013; Wijnen et al. 2015). However, as with all survey techniques (see ► Chap. 32, “Traditional Survey and Questionnaire Platforms”), DCEs are subject to a range of biases that need to be addressed in both design and analysis. While a DCE should encourage consideration of all attributes, individuals may still focus on a limited number or just one attribute and ignore the remainder. In addition to ignoring attributes, they may take mental shortcuts (heuristics) in completing the survey and show diminishing attention to attributes as the survey progresses (Cairns et al. 2002; Lloyd 2003; Hensher et al. 2012). Other biases include status quo (Salkeld et al. 2000), framing effects (Howard and Salkeld 2009), affect heuristics (Slovic et al. 2005), and a range of survey completion biases (left to right, top to bottom) (Campbell and Erdem 2015; see also ► Chap. 32, “Traditional Survey and Questionnaire Platforms”).

Cognitive burden increases with increasing number of attributes and choices, and most DCEs are limited to a relatively small number of attributes anticipated by the researchers as being most important. Over 90% of the health-related studies published from 2001 to 2012 had fewer than ten attributes with the majority having only four or five (Clark et al. 2014). Simplifying a DCE by limiting the number of attributes limits the ability to address complex questions, and participant’s choices may be increasingly determined by unknown factors, thus increasing the error component (Hensher et al. 2005; Lancsar et al. 2017). Conversely, completion and nonattendance errors increase with increasing complexity. These issues may be addressed to a varying extent by the use of qualitative studies, pilot testing with and without qualitative assessment tools such as “thinking aloud” during completion (Ryan et al. 2009), and the use of experimental designs aimed at limiting cognitive burden (Lancsar and Louviere 2008; Clark et al. 2014). In short, maximizing the value of DCEs requires careful planning and an iterative approach to design and assessment.

Discrete choice experiments are highly flexible in terms of research questions, design, and analysis. The number of choices, whether they are labeled or unlabeled, whether there is a status quo or opt-out choice, the number and type of attributes (numeric, descriptive, categorical), and the number of levels for each attribute can all be varied to suit the question of interest. The success of a DCE requires a balance between the ease of completion and complexity as being too simple or too complex both introduces errors. The key stages in conducting a DCE in health-related research is outlined in Fig. 5 adapted from Bridges et al. (2011). Each of these stages, described below, is applicable to both DCEs and BWS surveys.

1. Research Objectives

All health-related research questions need to be clearly defined, have a testable hypothesis, and follow a structured approach relevant to the area of research (e.g., clinical research, health economics, health service delivery, and so on). There needs to be a clear rationale for using a DCE over less complex alternate methods.

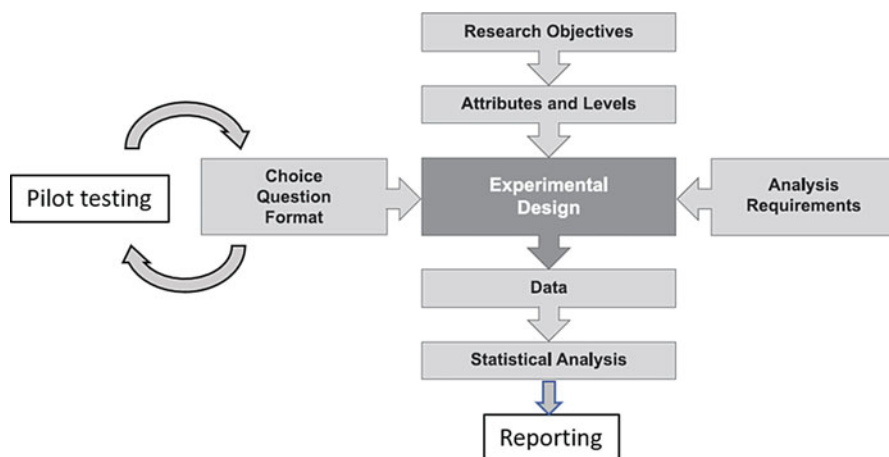


Fig. 5 A checklist for planning and conduct of discrete choice experiments in health-related research adapted from (Bridges et al. 2011)

2. Attributes and Levels

As the objective of a DCE is to provide, as far as possible, an unbiased evaluation of preferences, it is important that the attributes reflect those that are anticipated to be meaningful and likely to be the most important or relevant for the research question and the population. This will generally require a combination of literature reviews, opinions from expert panels, consensus meetings, and/or qualitative research including focus groups, structured interviews, and nominal groups techniques (see ► [Chaps. 23, “Qualitative Interviewing,”](#) and ► [42, “Consensus Methods: Nominal Group Technique”](#)). The evidence collected to support attribute selection should be relevant to the population. A DCE that aims to elicit patient preferences, which relies solely on the views of an expert panel, will exclude outcomes valued by patients not identified by the experts and/or place different levels of importance on outcomes. In situations where the number of possible attributes is large, the researcher must identify a subset of attributes for inclusion in the DCE, and these, as far as possible, should be those most relevant to the participants, and not experts or researchers. To minimize the influence of expert opinion or researcher bias in eliminating potential attributes, qualitative research techniques exploring the preferences of relevant stakeholder groups are an important component of the design process. As an example, [Fig. 6](#) shows the findings of a nominal group study undertaken to inform the design of a DCE addressing the trade-offs between outcomes associated with maintenance immunosuppression after a kidney transplant (Howell et al. 2012; Howell et al. 2017). Transplant recipients identified 47 unique outcomes all of which were relevant to the question and in theory could be included in the DCE. Analysis of the priority scores, the reasons underpinning the scores, and a pilot-scale DCE formed the basis for selection of just nine attributes in the final DCE (Howell et al. 2017). Attribute levels must

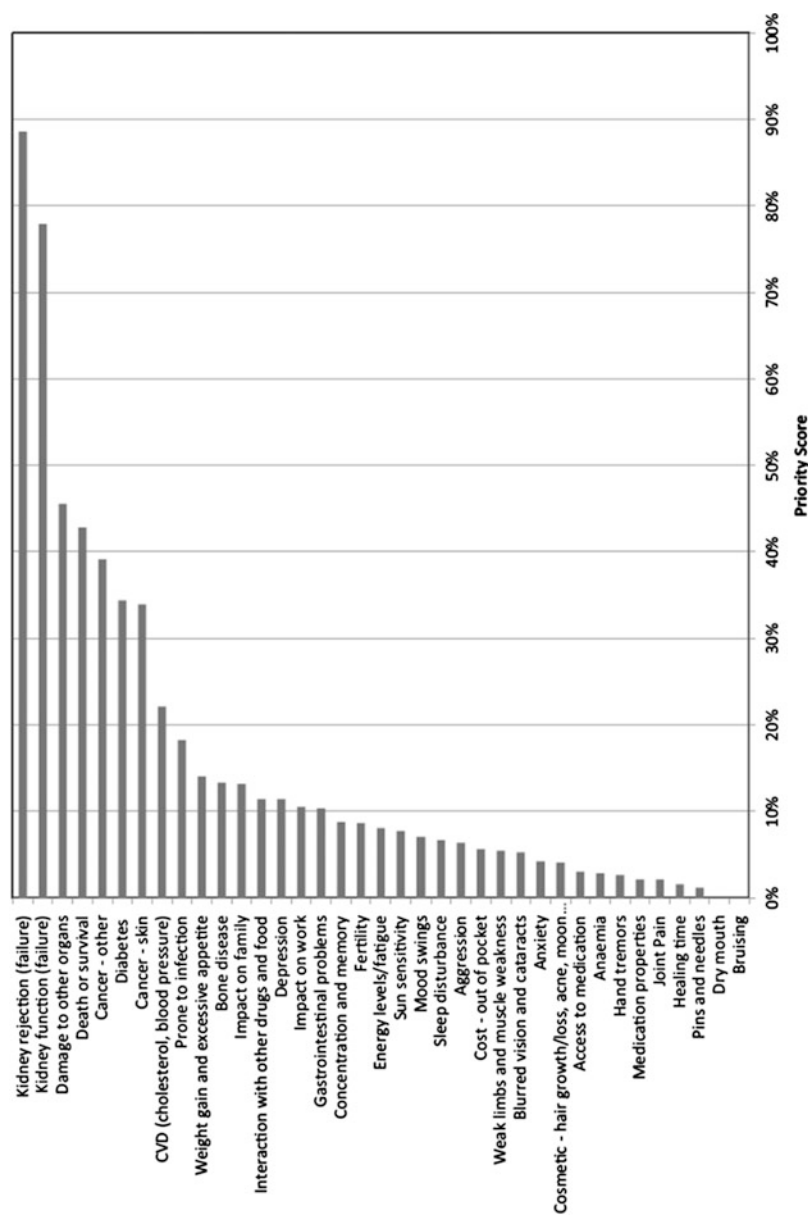


Fig. 6 Mean priority scores for outcomes associated with immunosuppression identified by kidney transplant recipients using the nominal group technique (Howell et al. 2012)

also be realistic and consistent with the research question. As far as possible, clinical outcomes should fall within expected ranges, while descriptive values should not be irrational or present implausible scenarios. However, the levels need to be sufficiently broad so as to influence choices made between profiles (Lancsar and Louviere 2008).

3. Question Formats

The DCE relies heavily on the construction of choice tasks that can be understood by the study population and an experimental design that combines attributes in a way that maximizes choice data while minimizing cognitive burden. Constructing questions also needs to consider the way in which profiles are presented, the number of choices within each choice set, whether they should be labeled, whether a status quo or opt-out option should be included, and the way in which attribute levels are described. Numeric levels may be numbers, words, pictograms, or a combination of methods. Figure 7 shows a single choice question from a DCE investigating the heterogeneity of women's preferences for breast screening and demonstrates the use of pictograms, numbers, and alternate ways of describing out-of-pocket costs (Vass et al. 2017).

4. Experimental Design

Experimental design refers to the process whereby a subset of all of the possible combinations of attributes and attribute levels is selected and combined into the individual choice sets or tasks (Lancsar and Louviere 2008). Good experimental design is key to achieving a DCE that balances the number of choice tasks and










	Programme A	Programme B	No Screening
Women who will have cancers detected by screening	3% 	14% 	None: no cancers detected
Women who will have an unnecessary follow-up	1% 	0% 	None: no unnecessary follow-up
Out-of-pocket cost to you of screening programme per screen	£20 per screen (£100 over your lifetime) 	£50 per screen (£250 over your lifetime) 	None: no cost to you
			

Fig. 7 Single choice task from a DCE investigating heterogeneity in women's preferences for breast screening (Vass et al. 2017)

thus complexity of the survey and the ability to estimate the choice models. There are a number of approaches to experimental design that are beyond the scope of this chapter to detail. Broadly speaking, experimental design is a balance between minimizing errors in responses and maximizing statistical efficiency and is dependent on the analytical requirements for the research question (Johnson et al. 2013). Sample size requirements are also linked to experimental design (Readers are referred to the following for further detail on experimental design: Rose and Bliemer (2013), Rose et al. (2008), Johnson et al. (2013)). It is also important to avoid implausible combinations of attribute levels in profiles, and constraints in the occurrence of certain combinations may need to be applied (Lancsar and Louviere 2008). The final design may also include additional choice sets aimed at identifying internal validity and the quality of the responses. This may take the form of duplicate choice sets for which the choice by a participant should be the same or a dominant choice set where only one response would be considered feasible or rational. While this can be used to exclude participants from the analysis, the size of the survey is increased, and the removal of participant responses assumes that “incorrect” choices are, from a clinical perspective, irrational or implausible which may not be the case for all participants. Consideration of what is implausible should be cognizant of the participant’s perspective rather than clinical considerations (Lancsar and Louviere 2008). Lancsar and Louviere (2006) argue against deleting responses that are thought to be “irrational,” as this may result in the removal of valid responses and RUT is able to cope with such data. Usual practice is to maximize data collected.

5. Analysis Requirements

As detailed in Section 3, there are multiple approaches to the analysis of choice data collected from a DCE. There is no single preferred approach, and the method chosen will reflect the research question and the extent to which simplifying assumptions will affect interpretation. As noted by Train (2009), more complex models that relax the simplifying assumptions of an MNL may not always be necessary. However, as the simplifying assumptions limit the ability of the DCE to evaluate preference heterogeneity and the influence of attribute and participant characteristics, more complex models are more commonly selected. Model selection should identify the simplest (parsimonious) approach to addressing the research question. Model selection influences sample size requirements and experimental design efficiency. Most analyses will also require respondent characteristics, and these should be identified in the planning phase.

6. Pilot Testing

Question formatting and experimental design are an iterative process with pilot testing used to refine the final design. The purpose of pilot testing is to test comprehension of the choices, attributes, and levels and the complexity of the task. Piloting may take the form of interviews or “think-aloud” studies (Ryan et al. 2009; Whitty et al. 2014) or having the survey completed by sufficient numbers to allow a preliminary estimation of a choice model (Howell et al. 2016). The regression coefficients from the pilot model can be used to further refine the design.

7. Data Collection

Attribute levels may be descriptive, categorical, ordinal, or continuous, and many DCEs will include a mix of formats (see Fig. 7). As such, most if not all attribute levels will need to be dummy coded for analysis and interpretation. The choice of coding is important for both analysis and interpretation (Lancsar and Louviere 2008; Hauber et al. 2016). A single choice from the survey will identify the profile selected and often the attributes and the attribute levels in the profile. The data format required for analysis varies according to experimental design (e.g., DCE vs. BWS), the proposed regression model, and software and may require substantial manipulation. Respondent characteristics may be also collected as part of the survey, and these also need to be coded for inclusion as interaction terms in the utility functions.

8. Statistical Analysis

The analysis of choice data can involve complex statistical analysis and choice models that vary according to the objective of the DCE. The requirement for secondary estimates such as trade-off and the willingness to pay introduces another layer of complexity as does the inclusion of respondent characteristics in the utility function. There are a number of general statistical and econometric software packages that provide built-in functions suitable for choice model estimation. Not all models are able to be estimated by all statistical software packages which may present a practical limit to the analysis (Lancsar et al. 2017) (see also ► Chap. 54, “Data Analysis in Quantitative Research”).

9. Reporting

The reporting of the results of the DCE has two prime objectives: firstly, to provide sufficient detail to enable an independent assessment of statistical validity of the model including statistical significance of all parameters and, secondly, to report the findings in the context of the research question. The meaning of attribute coefficients is often not intuitive and can be difficult to explain to the intended audience, and a range of approaches may be required beyond that needed to demonstrate validity. Regression coefficients can be expressed as odds ratios to aid interpretation; however given the mix of numeric and descriptive attribute levels, interpretation may also not be intuitive (see also ► Chap. 56, “Writing Quantitative Research Studies”).

5 Conclusions and Future Directions

In summary, DCEs are well suited and widely used to elicit the stated preferences of patients, their caregivers, the general public, and health professionals for a range of health-related questions. They are underpinned by a well-established theoretical framework and have the flexibility to address a wide range of questions. The prime limitation in addressing complex health decisions is the cognitive demand of the survey associated with multiple profiles, multiple attributes with multiple levels, and the expectation that individuals will give attention to all scenarios and attributes equally. The more complex the DCE, the greater the errors, and the more

biased the estimates. Best-worst scaling surveys have been used as one approach to minimize complexity. Careful planning and implementation are required to ensure the DCE provides reliable and meaningful answers to the research question. Given the flexibility and robust framework for assessment, DCEs are becoming a commonly used tool for preference elicitation across clinical research, health economic evaluation, health service delivery, and patient-centered research. The increasing availability of large data sets from registries of prescription and medical service use and the ability to link these to individual patients raise the potential for DCEs to combine this revealed data with stated preferences using econometric models to explore the extent to which health services align with preferences and values. Given the increasing trend for inclusion of the preferences and values of patients, their carers, and the general public in decisions related to all aspects of health service delivery, DCEs and BWS surveys are likely to become more widely used.

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Randomized Controlled Trials

37

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Contents

1	Introduction	646
2	Randomized Controlled Trials: General Aspects	647
3	Features of RCTs	648
3.1	Type of Randomization	648
3.2	Allocation Concealment	649
3.3	Blinding	649
3.4	ITT Analyses	650
3.5	Sample Size Calculation	651
3.6	Pilot Studies	652
4	Protocol Design	653
5	Protocol Registration	653
6	Categories of RCTs	654
6.1	Parallel	654
6.2	Factorial	654
6.3	Cluster	655
6.4	Crossover	656
7	Superiority, Equivalence, and Non-inferiority Trials	657
8	Reporting of RCTs	657
9	Shortcomings of RCTs	658
9.1	Pragmatic	658
9.2	Comparative Effectiveness Research (CER)	659
10	Conclusion and Future Directions	659
	References	660

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Abstract

This chapter covers the current gold standard for evaluating the effectiveness of therapeutic interventions, the randomized controlled trial (RCT). Key features of the RCT, regardless of sub-type, are randomization, allocation concealment, and blinding. These key features help reduce bias and the influence of confounding variables, making the randomized controlled trial eminently suitable to determine cause and effect relationships. Protocol design and registration prior to trial onset are important factors in determining the quality of the trial, and various trial design sub-types, including parallel, factorial, crossover, and cluster, are outlined and the strengths and weakness of each examined. Various checklists such as SPIRIT and CONSORT can be used to ensure proper reporting of both trial protocols and trial findings, to ensure clear, concise reporting. Finally, the shortcomings of RCTs and newer trial designs, such as comparative effectiveness research and pragmatic studies, designed to overcome some of these issues are examined, and ways to make clinical trial results more clinically applicable are discussed.

Keywords

Randomized controlled trials · Blinding · Factorial · Pragmatic · Factorial · Cluster · Crossover · Pragmatic · Comparative effectiveness

1 Introduction

Not everything that counts can be counted, and not everything that can be counted, counts –
Albert Einstein

Humans have continuously attempted to find a cure for disease. In pre- and ancient history (from the dawn of civilization to AD 1000), medicine was a product of cultural beliefs and theories and, later, some clinical experience. In prehistoric times, illness was viewed as a spiritual event and was treated likewise. Later, healers used herbal or surgical treatments that seemed to work (using clinical experience to judge). The Arabs began studying chemistry and advocating the use of chemical medications and defined rules for adding, subtracting, multiplying, and dividing in AD 800 (Mayer 2004).

During the Renaissance and Industrial Revolution, there were revolutionary changes in the understanding of the basic sciences and advances in mathematics and statistics. Vesalius rejected Galen's incorrect anatomical theories (which were based on the dissection of animals), and Paracelsus advocated for the use of chemical instead of vegetable medicines. In 1202, Fibonacci first introduced numbers to the European civilization. Prior to this, the use of Roman numerals had made complex calculations impossible. Probability theories developed, and in 1619, Gataker expounded on the meaning of probability by noting that natural laws, and not divine providence, governed these outcomes (the ancient Greeks had previously believed that the Gods decided all life). The microscope was invented in the sixteenth century, and Harvey put forward the theory of blood circulation in the seventeenth century.

Development of modern medicines in the eighteenth century saw the introduction of digitalis, the use of inoculation against smallpox, and the postulation of the existence of vitamins. Pascal refined the theories of statistics, and actuarial tables began to be used to determine insurance for merchant ships (Mayer 2004).

These changes set the scene for a new approach to defining the best current medical practice in the twentieth century. However, apart from a few pioneers, the art of medicine up to this time remained largely anecdotal and continued to be based on deductions from experiences and induction from physiological mechanisms (Mayer 2004). Sir Richard Doll wrote that in the 1930s, new treatments invariably arose as a result of physicians observing the effects in small numbers of patients (the case series) (Doll 1998). This method of using uncontrolled observations may be reliable when the intervention in question has dramatic effects, such as those of insulin on type I diabetes (Gluud 2006). For the majority of interventions though, especially for those with an outcome that is somewhat subjective, observation alone introduces bias and fails to control for factors that may lead to an apparent improvement that is not related to the intervention in question (confounding factors). Pierre Louis illustrated this in the 1800s when he demonstrated, via a retrospective analysis of a case series, that bloodletting (the most popular therapeutic invention of the day) was of no benefit in pneumonia (Doherty 2005).

During the twentieth century, biomedical research progressed in leaps and bounds, beginning with a rise in the numbers of research studies in physiology and other basic sciences and a move away from empirical observation of cases. Austin Bradford Hill published a series of articles in *The Lancet* in 1937 on the use of statistical methodology in medical research and went on to direct the first true modern randomized controlled trial (RCT) to be published – which examined the efficacy of streptomycin versus standard care for the treatment of pulmonary tuberculosis in 1948. During the 1950s, the RCT became the standard for excellent clinical research. Archie Cochrane later drove the movement to perform systematic reviews of RCTs (Mayer 2004).

2 Randomized Controlled Trials: General Aspects

Even though the first RCT was not published until 1948, controlled trials have been documented since the Old Testament. The Book of Daniel describes an experiment comparing the effects of a vegetarian diet with the standard Royal Babylonian diet in servants. James Lind, a naval surgeon, conducted a small RCT ($n = 12$) while on board the HMS Salisbury in 1747, which compared the effects of citrus fruit (two oranges and a lemon daily) against five other control groups, who had other additives to their diet (vinegar and seawater being among these), and observed that the citrus group recovered from scurvy after 14 days (Doherty 2005).

The RCT is now considered the “gold standard” in evaluating the effectiveness of a therapeutic intervention. It attempts to control or minimize confounding factors that affect outcomes and distort apparent treatment effects (Manchikanti 2008). A well-designed RCT provides the best evidence on the efficacy of healthcare

interventions and should identify situations where the difference in outcomes between two or more intervention groups was not due to chance or confounding factors (Moher et al. 2001).

The main features of an RCT that help to minimize bias are *randomization*, *allocation concealment*, *blinding*, and the use of an *intention-to-treat (ITT) analysis*. Inadequacies in these key methodological approaches often lead to a distortion of treatment effects, usually by overestimating the effects of the intervention (Schulz et al. 1995). The extent to which bias is controlled, and to which results reflect the true effect of the intervention, is referred to as internal validity (Juni et al. 2001). For academic rigor, RCTs should conform to the CONSORT (Consolidated Standards of Reporting Trials) statement, which was developed to improve the quality of reporting of RCTs (Moher et al. 2012) (see later section Reporting of RCTs).

3 Features of RCTs

3.1 Type of Randomization

Randomization, or random allocation, is the process by which each participant has a known probability of receiving each intervention before one is assigned. However, the actual intervention is determined by a chance process and cannot be predicted (Moher et al. 2001). Using chance to decide treatment allocation eliminates selection bias and can ensure that prognostic factors and unknown confounding variables are similar between comparison groups, as these are expected to balance out on average with randomization (The James Lind Library 2007a). Proper randomization also facilitates blinding (which reduces bias after assignment of interventions) and permits the use of probability theory to express the likelihood that any difference in outcome between two intervention groups is due to chance. Randomization is a crucial component of high-quality RCTs (Moher et al. 2001).

Adequate randomization methods include a computer-generated random sequence, drawing from a table of random numbers, lots or envelopes, tossing a coin, or shuffling cards or dice. Using alternation, date of birth, or case record numbers does not constitute adequate randomization (Juni et al. 2001). Non-randomized studies may produce misleading results even when comparison groups appear similar (Manchikanti 2008) as they tend to overestimate treatment effects by up to 160% or underestimate effects by up to 76% (Gluud 2006).

There are a range of different types of randomization strategies including simple, block, stratified, and adaptive, and selection will vary depending on the study and intervention design. *Simple* randomization involves using a single sequence of random assignments for each participant per treatment group (e.g., a coin flip to determine treatment (heads) or control (tails)) (Altman and Bland 1999b). *Block* randomization allocates participants into equally sized blocks/groups. The number of blocks should be a multiple of the block size, the product of which equals the total sample size (Altman and Bland 1999a). *Stratified* randomization allows for the control of covariates that may influence the trial's results (e.g., age, disease severity).

Once covariates have been identified, participants are then allocated to separate blocks for each combination of covariates, and then simple randomization is conducted for each block (Suresh 2011). *Adaptive* randomization involves sequentially assigning participants to treatment groups based on the previous group assignment of other participants (Kalish and Begg 1985). Adaptive randomization is typically used when controlling for covariates to allow for an even distribution of potentially outcome altering covariates between treatment allocations.

3.2 Allocation Concealment

For the randomization process to be considered adequate, it must both be generated by a chance process and followed by proper allocation concealment (Moher et al. 2001). Allocation concealment is the process used to ensure that the individual deciding to enter a participant into an RCT does not know (and cannot influence) the comparison group into which that individual will be allocated (Higgins et al. 2011). Proper randomization followed by adequate allocation concealment protects the allocation sequence and eliminates selection bias by shielding those who enroll patients from being influenced by knowledge of the next allocation. The use of a third party (e.g., independent pharmacies or a centralized telephone system) is ideal. Sequentially numbered opaque sealed envelopes (SNOSE; as long as they cannot be transilluminated) or numbered containers are also acceptable and can provide a more cost-effective option, providing the procedure is followed diligently (Doig and Simpson 2005). Writing the participant's name and details on envelopes prior to opening them is suggested to ensure adequate allocation concealment (Moher et al. 2001). Allocation concealment methods can be adopted to facilitate a variety of randomization types including those outlined above (simple, block, stratification, and adaptive). Studies which are labeled randomized but fail to report adequate allocation concealment yield larger estimates of treatment effects and may exaggerate them by up to 30% (Schulz et al. 1995).

3.3 Blinding

Blinding refers to the process of keeping participants, healthcare providers, evaluators, and sometimes those who manage and analyze data unaware of treatment allocation so that they will not be unduly influenced by this knowledge. When healthcare providers and participants are adequately blinded, it eliminates performance bias that is associated with patient and investigator expectations (Gluud 2006). Blinding of participants prevents treatment responses being influenced by expectations. That is, participants may have favorable expectations if assigned to the treatment group or disappointment if assigned to a control group, while healthcare providers may treat participants differently if group assignment is known (Moher et al. 2001).

Unlike allocation concealment, blinding may not always be appropriate or possible (Manchikanti 2008). The relevance of using blinding varies according to circumstances. Blinding and the use of placebo controls are not always possible or ethical, for example, in trials involving surgical procedures (Moher et al. 2001). Some interventions may be difficult to blind, for example, drugs that cause significant adverse effects (Gluud 2006).

The use of blinding assists in evaluating the efficacy of an intervention. For example, the use of placebo controls attempts to control bias by controlling for non-specific effects (all potential influences on the apparent course of the disease apart from those arising from the intervention itself) (Manchikanti 2008). The earliest use of a placebo control involved a sham device (made of wood) to test claims that a metal tractor cured through “electrophysical force.” A crossover study failed to detect any benefit from the metal tractors (The James Lind Library 2007b). Placebo controls should be identical to the intervention in taste, smell, appearance, and so on (Gluud 2006) but not contain the actual drug or procedure.

However, not all placebo controls are completely inert or inactive, for example, the injection of sodium chloride into a nerve root or joint may exert a significant pain-relieving effect. Placebo-controlled RCTs have the advantage of providing the maximum ability to distinguish adverse effects from a drug or procedure but may create ethical concerns and patient and physician practical concerns and may cause patients to withdraw due to perceived lack of treatment response even if they were assigned to the active group (Manchikanti 2008).

Even in cases where blinding of patients or investigators is not achievable, blinding of outcome assessors is always possible and may theoretically be one of the most important considerations, preventing detection bias (Gluud 2006). It is more important when the outcome measures involve some subjectivity, such as assessment of pain or functional status, but is probably less important in situations such as assessing the effect of an intervention on mortality (Manchikanti 2008).

Blinding may be evaluated; however, if participants do successfully identify their assigned interventions more than would be expected by chance, it may not necessarily indicate that blinding was unsuccessful (Manchikanti 2008). Adverse events may also provide clues, as might treatment response; hence, participants are more likely to assume that a favorable outcome or the experience of side effects means they were allocated to the active intervention (Moher et al. 2001). Trials in which participants and caregivers/outcome assessors are not blinded exaggerate treatment effects by an average of 17% (Schulz et al. 1995). In a placebo-controlled trial, the assessments by unblinded, but not blinded, investigators showed an apparent benefit of the intervention (Moher et al. 2001).

3.4 ITT Analyses

RCTs rarely run smoothly, and deviations from protocol and loss to follow-up are sometimes inevitable. Analyzing results on an “intention-to-treat” (ITT) basis is recommended to reduce attrition bias. An ITT analysis is generally conducted by

including all patients, regardless of eligibility, treatment received, withdrawal, or deviation from protocol (Hollis and Campbell 1999), or all available participants according to their original group assignment (Moher et al. 2001). However, there is still debate about the validity of excluding specific cases within each of these categories, and full application of an ITT analysis is only possible when outcome data are available for all randomized participants (Hollis and Campbell 1999) at all prespecified points during the trial (Juni et al. 2001). It is common for some participants to not complete a study, and these participants are not included in the ITT analysis (Moher et al. 2001). It has been suggested that ITT analyses may be more suitable for trials of effectiveness rather than explanatory trials of efficacy (Hollis and Campbell 1999).

There is no consensus on how to deal with missing data (Hollis and Campbell 1999). Suggestions for imputation include carrying forward the last observed response or calculating the most likely outcome based on that of other participants (Gluud 2006), but assumptions about missing data cannot be verified in most clinical trials (Hollis and Campbell 1999). Here, prevention is the key – all attempts should be made to minimize dropouts and missing data (Gluud 2006). ITT analyses may be less important in terms of internal validity than allocation concealment, randomization, and blinding. When these components were adjusted for, trials that excluded participants yielded similar treatment effects compared with trials that did not exclude participants (Schulz et al. 1995).

Presenting the flow of participants through a trial is highly recommended. This should include descriptions of the numbers of participants randomly assigned, receiving intended treatment, and completing the protocol, and analyses for the primary outcome (preferably through the use of a diagram, such as the CONSORT flow diagram; see below) (Moher et al. 2012). The possibility of attrition bias should be considered and discussed in reports on the trial (Juni et al. 2001). Describing those participants who dropped out may be important for external rather than internal validity (Moher et al. 2001).

3.5 Sample Size Calculation

Even after making efforts to minimize bias through randomization, allocation concealment, blinding, and ITT analyses, chance may still produce misleading results. An apparent difference between treatment groups may be purely due to chance alone (The James Lind Library 2007c); alternatively, there may not be enough participants to show differences between groups. There are two major types of statistical errors: type I error, concluding that there are statistically significant differences when actually there are none (false positive), and type II error, concluding that there are no differences between groups (e.g., due to small sample size) when in fact there is a difference (false negative). Sackett (1979, p. 61) says this clearly: “Samples which are too small can prove nothing; samples which are too large can prove anything.”

A study is considered adequately powered when it has a high probability, through a minimum sample size, of detecting a statistically *and* clinically significant

difference between groups. Larger sample sizes are required to detect more modest differences. Formal power calculations are recommended. Many studies are considered too small to have enough power to detect a difference between groups, therefore increasing the likelihood of type II error (Moher et al. 2001).

3.6 Pilot Studies

Randomized controlled trials are unwieldy tools, with practical problems being common. Some trials may never be completed due to issues relating to recruitment or acceptability of the intervention. Despite the tidy way that RCTs are reported when published, in reality they rarely run smoothly. RCTs are also relatively expensive to run, and the bodies that fund these studies have to consider what the probability is that a study will be completed and yield useful data, in addition to balancing ethical elements such as participant burden, risk of side effects, and reimbursement for participation. Increasingly, pilot studies are required to justify the launch of a large-scale RCT (Arnold et al. 2009).

A pilot study is a smaller-scale preliminary version of a larger RCT (the parent study) with similar methods and procedures (Jairath et al. 2000) that are specifically designed to inform the design and conduct of the parent study (Arnold et al. 2009). The term pilot study does not apply to all small-scale studies; studies with small sample sizes are only considered pilot studies if they directly or indirectly yield data to justify a larger study (Jairath et al. 2000).

Pilot studies must have explicitly defined objectives (Arnold et al. 2009). These usually relate to an assessment of feasibility of the trial and may extend to the feasibility and acceptability of the intervention, the trial design and procedures, data collection, and data analysis (Jairath et al. 2000). Costs and timelines are also assessed. When research funding is sought, an additional objective is to gather sufficient preliminary data to justify a grant award (Jairath et al. 2000). Findings from pilot studies should be used to improve trial design as appropriate.

Because they are usually designed to be a dress rehearsal for the full performance, simulating all the procedures of the parent study (including randomization and allocation concealment), pilot studies offer a unique opportunity to identify and prepare for the challenges of conducting a large RCT (Feeley et al. 2009). They function as a test to ensure future trials are designed optimally and can be implemented in practice (Arnold et al. 2009) and serve to justify planned research (Jairath et al. 2000). As such, they contribute significantly to increasing the methodological rigor of an RCT.

There are important limitations to pilot studies. Sample sizes are small, and overanalysis of outcomes (e.g., sub-analyses) should be avoided and de-emphasized as these are likely to be significantly underpowered. Hence, pilot studies cannot be used to determine treatment effects. They also cannot be relied on to provide valid estimates of event rates and should be used cautiously or not at all to guide power calculations (Arnold et al. 2009).

4 Protocol Design

Writing a clinical trial protocol is important for a number of different reasons. A protocol helps outline key steps in the trial for those involved in coordinating and delivering the trial intervention. When written correctly, it also provides the detail required for external review, whether by ethics committees or institutional review boards, funding agencies, and other researchers to assess the aims, interventions, and outcomes of the work as well as to identify any ethical concerns in the conduct of the trial. The guidelines for Good Clinical Practice (GCP), first published in 1996, are an international ethical and scientific quality standard for designing, conducting, recording, and reporting trials that involve the participation of human participants (ICH 1996). The objective of these guidelines is to provide an international unified standard for ensuring that the rights of participants are protected and that data generated by the trial are credible. However, writing a complete and clear trial protocol that adheres to the GCP standard can be challenging, especially for those new to the field, and missing key components can lead to having to submit multiple amendments to the original protocol. To help guide authors in writing complete and concise trial protocols, there are a number of expert guidelines, the most commonly used being the SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) statement for clinical trials (Chan et al. 2013). The SPIRIT statement provides guidelines for a minimum set of scientific, ethical, and administrative elements that should be addressed in a clinical trial protocol that adheres to GCP standards and provides a useful checklist to cover off the content of each section of the clinical trial protocol. The entire SPIRIT checklist is outside the scope of this chapter and is being updated on an ongoing basis to best reflect any changes in reporting standards; therefore, checking the latest version will provide the most up-to-date guidance.

5 Protocol Registration

A common practice in recent years is the publication of the clinical trial protocol during the recruitment phase of the clinical trial itself. This is often performed in conjunction with registering the trial itself in a clinical trial registry. There are a number of clinical trial registries which can be location specific, such as the ANZCTR for Australian and New Zealand trials (<http://www.anzctr.org.au>), while others such as ClinicalTrials.Gov (<http://www.clinicaltrials.gov>) index a number of international registries. The motivation behind trial registration is multifaceted, primarily driven by the observation that either negative results are not published, their hypotheses are altered after the data has been analyzed or only certain outcome measures are reported, to make the findings more positive (Fanelli 2010). Additionally, registration helps prevent duplication of work that is already ongoing. Preregistration of clinical trials is now mandatory for most academic journals (De Angelis et al. 2004) to try and ensure that all preplanned outcomes are included in the final manuscript, and registration before the enrolment of the first participant is strongly

encouraged. However, individual journal editors have been slow to enforce this convention, and the implementation of this policy is uneven, at best (Scott et al. 2015). Publication of clinical trial protocols often occurs in specific journals catering to trial protocols. The benefit for authors is this allows elaboration on the somewhat terse information contained in clinical trial registries and allows reference back to the original protocol in any subsequent publications, providing more detail than might otherwise be available.

6 Categories of RCTs

There are four current major categories of RCT design commonly used in medical research: parallel, factorial, cluster, and crossover. Specific designs provide unique advantages and disadvantages.

6.1 Parallel

The most common type of RCT uses two parallel groups, often considered the “classic” RCT design, where participants are randomized to either an active treatment (A) or control group (B). Each group does not require exactly equal numbers, but in most cases, an almost equivalent number would be expected in each group, unless there had been an unequal randomization ratio specifically chosen (e.g., A to B ratio: 3:1). Each group receives only one type of treatment during the treatment phase (in contrast to crossover designs). The control group is commonly a placebo but increasingly can be either the current “gold standard” treatment or even another dose of the same medication. Parallel studies would be preferred over crossover designs if the disorder is cyclical (e.g., menstrual pain), if the condition is expected to progress in severity over time (e.g., dementia), or if the condition is acute (e.g., musculoskeletal pain).

6.2 Factorial

A factorial design includes two or more “factors” and two or more “levels” for each factor. The most common variant is a 2×2 *factorial design*, where there are two factors and two levels for each factor. This type of design allows the researcher to examine both the influence of each factor separately (the main effects) and the interaction between any of the factors, on the outcome variable(s). This is more efficient than running a parallel RCT where the influence of a single factor is usually examined. Running multiple parallel RCTs on different factors will also not allow any possible interaction between factors to be observed. An example of a 2×2 factorial design would be examining the effect of a restricted versus normal calorie diet and resistance training exercise versus rest on the outcomes of body weight and maximum leg press weight. In this example, calorie intake and exercise are factors,

while restricted calories versus a normal diet (without calorie restriction) and rest versus resistance training are levels for each factor, respectively. This would result in four possible comparisons:

1. Calorie restriction and rest
2. Calorie restriction and resistance training
3. Normal diet and rest
4. Normal diet and resistance training

In a parallel group design, this would equate to two separate studies, one examining the effect of calorie restriction and another the effect of resistance training. However, factorial design allows for the evaluation of both factors separately in one trial (the main effects) as well as the possible interaction between the two (i.e., the potential effect of one factor on another on the outcome). If calorie restriction was superior for weight loss compared to no calorie restriction, regardless of exercise, we would say there is a main effect for calorie intake, reporting the factor rather than the level. For examining interactions, we might find that while the group using calorie restriction and resistance training may cause the greatest bodyweight reduction, it may reduce maximum leg press weight due to the significant calorie deficit. This would be an interaction between calorie intake and exercise. Again, we report the *factors* not the levels. This ability to examine multiple factors in a single experiment and to look for interaction effects is a significant strength of the factorial design.

6.3 Cluster

Cluster randomized trials involve randomizing intact groups of participants, rather than individuals, and typically involve randomizing by site or study location (e.g., hospitals, clinics, communities) (Cornfield 1978). The primary advantage of cluster randomization is to avoid contaminating the intervention and control groups between participants. Other advantages include administrative efficiency and enhanced participant compliance. Cluster randomization is an appropriate trial design for educational intervention trials in healthcare settings, for example, a trial that compares changes in health outcomes between patients with end-stage kidney disease trained by nurses who received an educational intervention versus usual care. If nurses within the same renal unit were randomized to either the treatment or usual care group, it is likely that there would be a significant contamination between the groups, with nurses in the usual care group having the potential to be exposed to elements of the training received by the training group (e.g., patient remarks, overhearing conversations about the training, seeing the training materials, and so on). Some RCTs must employ a cluster randomized design by necessity, such as community trials that test the efficacy of public health interventions (“Community Intervention Trial for Smoking Cessation (COMMIT): I. cohort results from a four-year community intervention” 1995).

The primary disadvantage of cluster randomization compared to individual randomization is the “design effect” which involves lower statistical efficiency caused by variance inflation due to clustering (i.e., more participants are required to reach the same statistical power). Other disadvantages include clustering or collinearity between the sampled individuals within a cluster (i.e., high degree of similarity in the outcome measures between individuals within clusters), in addition to an increased level of complexity in the design and analysis of the data compared to RCTs involving individual randomization such as in parallel trial designs (Donner and Klar 2004).

6.4 Crossover

Crossover studies are repeated-measures studies (i.e., within participants), where participants receive different treatments in a different sequence depending on their group allocation. In contrast to parallel group studies, where participants receive treatment A or B, in crossover designs, each participant receives both A and then B or vice versa. Crossover designs offer three primary advantages over parallel designs: statistical efficiency, reduction of confounding variables, and a decreased ethical burden compared to parallel group trials. Increased statistical efficiency in crossover designs (Viboud et al. 2001) means that fewer participants are required in a trial compared to a parallel design to reach the same statistical power because each participant effectively acts as their own control. As participant recruitment is usually the most costly and difficult part of running an RCT, this can be a significant advantage. As each participant is their own control, the problem of imbalance of covariates/confounding variables (such as age or weight), which may occur in parallel RCTs, is solved. Finally, for placebo-controlled trials, there may be ethical concerns about withholding suitable treatment in parallel-design RCTs. This is especially relevant where those delivering the intervention are not blinded and may feel significant conflict around delivering a known placebo intervention (Barr et al. 2016). Crossover trials avoid this concern due to the fact that each participant will receive both active and placebo treatments.

Despite these advantages, there are several significant drawbacks that reduce the real-world usefulness of crossover studies. Carry-over effects, where the effect of the first treatment (treatment A) may still be present when starting the second treatment (treatment B), is of significant concern. This can be avoided by using a “washout” period, where a period of time is added between the two treatments, so that any effects from treatment A have completely resolved prior to starting treatment B (and vice versa). However, this requires detailed knowledge of the pharmacokinetics of the treatment and other parameters which are often not clear. Additionally, if using therapies such as psychotherapy or acupuncture where the effects may be long-lasting, it may be inappropriate to use crossover studies. Order effects, where the order of the treatment can affect the outcome, are also important. If treatment A is time-consuming, such as an exercise program, participants may lose motivation by the time they start treatment B. Alternatively, they may have become better by

“practicing,” so if treatment A and treatment B are both different exercise programs, participants may be better at whichever they are assigned to as the second treatment. Crossover designs are not suited to conditions where the condition may change significantly (e.g., an acute pain episode may have resolved, or a degenerative disease may have progressed) by the time that the second treatment is given; these are called “period effects.” They are, however, suited to chronic conditions that do not change significantly over time (e.g., hypertension). Finally, as each participant is their own control and thus contributes several “sets” of data, each dropout results in a much greater proportion of missing data than would be seen in a parallel trial.

7 Superiority, Equivalence, and Non-inferiority Trials

RCTs, regardless of category, can be used to determine if a treatment is “superior” to a current treatment or placebo (superiority trial), “roughly the same” as a current treatment (equivalence), or “not much worse” than a current treatment (non-inferiority trial) (Lesaffre 2008). In medical research, the superiority trial is the most common (Piaggio et al. 2006), especially when comparing the active intervention to a placebo. Both equivalence and non-inferiority trials compare the intervention to an active comparator and are most commonly used during the development of a new intervention, such as a new version of a medication. The distinctions of “superior,” “roughly the same,” and “not much worse” are based on both statistical and clinical significance (Ganju and Rom 2017), where trial findings may be statistically significant (due to type II error in a large trial) but not necessarily *clinically* significant. Generally, the margin of clinical significance for equivalence and non-inferiority will be the largest margin possible before a clinically noticeable difference that would impact clinical practice is seen (Committee for Proprietary Medicinal Products 2001). The type of trial must be decided a priori, and only one trial type can be used at any one time. It must not be altered after the data has been examined.

8 Reporting of RCTs

Similar to the SPIRIT guidelines outlined above for publishing trial protocols, the CONSORT statement (Moher et al. 2001, 2012) is an established set of guidelines for the reporting of RCTs. The aim of CONSORT is to provide a clear and standardized set of minimum requirements for the reporting of RCTs in order to facilitate “complete and transparent reporting, and aiding . . . critical appraisal and interpretation” (The CONSORT Statement 2017). CONSORT also includes a 25-point checklist and flow diagram that many peer-reviewed journals require RCT authors to complete when making a submission. The CONSORT statement and checklist are subdivided into the major sections related to reporting an RCT (title, abstract, introduction, methods, results, and discussion) and focus on essential aspects of trial design, for example, participants, interventions, outcomes, sample size, randomization, blinding, statistical methods and analyses, participant flow,

recruitment, baseline data, numbers analyzed, outcomes including effect sizes, harms, limitations, generalizability, and interpretation of results. As with the SPIRIT guidelines, readers should check for the latest version of the CONSORT statement before use.

9 Shortcomings of RCTs

Although RCTs are a valuable way of evaluating therapeutic interventions, they are not a perfect approach. The disadvantages of RCTs are that they allow for less generalizability, are slow and expensive to conduct, and cannot answer as broad a range of questions as observational studies. RCTs also do not simulate real practice – they attract a particular type of patient, who may be more willing to comply with interventions (which can introduce selection bias), do not have multi-morbidity, and result in more attention and education given to patients than would normally be afforded in usual clinical practice (Katz 2006). In reality, patients are often far more complex than those enrolled in RCTs with narrowly defined eligibility criteria. RCTs also rarely study long-term outcomes and require large sample sizes to achieve statistical significance in order to equalize confounding factors (Manchikanti 2008). However, there are some possible design modifications that can be used to alleviate the shortcoming of RCTs.

9.1 Pragmatic

Every clinical trial is situated somewhere along the pragmatic-explanatory continuum, with few trials being purely pragmatic or purely explanatory (Thorpe et al. 2009). Pragmatic trials “help users choose between options for care” and answer the question “does this intervention work under usual conditions?,” while explanatory trials “test causal research hypotheses” and answer the question “can this intervention work under ideal conditions?” (Thorpe et al. 2009, p. 464). Pragmatic trials tend to follow on from explanatory trials in pharmacological research (Thorpe et al. 2009). In other words, pragmatic trials inform practice and policy as to whether an intervention works under usual conditions, compared with usual care, while explanatory studies inform as to whether the observed effect is due to the intervention or due to other non-specific factors, such as regression to the mean, the placebo response, and spontaneous improvement.

Explanatory trials have the advantage of maintaining high internal validity or the ability to reduce bias or systematic error; some of this bias can be prevented by blinding. However, external validity, or the ability to generalize the findings, may be compromised. On the other hand, pragmatic trials may have higher external validity than explanatory trials, due to less stringent eligibility criteria and an intervention that closely reflects clinical practice. This may come at the expense of lower internal validity, and larger sample sizes may be needed (Gartlehner et al. 2006).

Pragmatic studies provide valuable evidence about whether an intervention does what it is purported to do. However, pragmatic trials do not inform why the treatment worked – was it because of the specific (active) effect of the treatment or non-specific effects? As an editor so eloquently wrote in the *British Medical Journal* in the middle of the twentieth century: “In treating patients with unproved remedies we are, whether we like it or not, experimenting on human beings, and a good experiment well reported may be more ethical and entail less shirking of duty than a poor one” (Hill 1952, p. 119).

9.2 Comparative Effectiveness Research (CER)

Comparative effectiveness research (CER) is defined as “the generation and synthesis of evidence that compares the benefits and harms of different treatment options to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care” (Witt et al. 2012, p. 1). Additional CER has been recommended particularly for clinical conditions that are “common and costly to society and that have a great degree of variation in their treatment.” Features of CER include generating evidence to inform a specific clinical decision and comparison of at least two interventions, each with the potential to be the “best practice.” Additionally, CER is conducted in the routine clinical setting to which the intervention belongs.

Larger sample sizes are needed for CER, which is a practical and financial challenge, as recruitment is a considerable challenge in clinical trials. However, broadening eligibility criteria could assist with feasibility of recruitment. Larger sample sizes would also allow for adequately powered subgroup analyses, assessing the impact of confounding factors such as use of co-interventions, and different clinical styles. Multicenter or multinational trials may be conducted to further expand external validity. Some novel methods have been suggested for CER RCTs such as dynamic allocation to balance treatment arms across prognostic factors, rank minimization, response-adaptive allocation, partially randomized patient preference design, and cluster randomization (Witt et al. 2012).

The disadvantages of CER are that it involves a greater financial cost due to the larger sample sizes needed and considerable time and effort in the protocol design phase if methods such as stakeholder consultation and consensus methods are to be used. CER also does not inform on component efficacy.

10 Conclusion and Future Directions

RCTs are currently the gold standard for evaluating the effectiveness of therapeutic interventions. Careful a priori choices regarding which type of RCT is chosen to answer the specific clinical question are vital to ensure that the strengths of the RCT are maximized while avoiding the limitations. Where suitable, crossover and factorial designs can provide increased statistical power compared to parallel groups, while cluster and crossover designs can increase participant compliance. Both are

significant in terms of cost reduction, cost being a major disadvantage to most RCTs, due to smaller sample sizes and reduced dropouts. The standard features of RCTs, random allocation, allocation concealment, and blinding, provide a countermeasure to confounding factors and bias. However, they must be implemented carefully to ensure that they can perform these functions; simply performing an RCT does not equate to good evidence (Landorf 2017).

Good-quality, randomized controlled trials are still lacking for a surprising number of common interventions used in healthcare and are relatively rare in many non-pharmaceutical interventions such as surgery, physical activity, or diet. While placebo-controlled, parallel RCTs are still the most common design, especially in efficacy studies, these do not always provide the most clinically relevant information and can be difficult to design when using more complex interventions such as lifestyle changes. Therefore, if the focus is on changing clinical practice, researchers should consider pragmatic and comparative effectiveness research frameworks to ensure that their results can be translated into changes in practice. Future RCTs need to be undertaken with these research designs in mind, especially when considering healthcare challenges, such as obesity, that require a reflection of the complex nature of the problem when considering the trial design to ensure that relevant, effective interventions are developed and deployed.

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Measurement Issues in Quantitative Research

38

Dafna Merom and James Rufus John

Contents

1	Introduction	664
2	Reliability	665
2.1	Sources of Risk for Reliability	666
2.2	Types of Reliability and Their Associated Statistical Methods	668
3	Validity	669
3.1	Types of Validity Evidence and Their Associated Statistical Methods	670
3.2	Which Validation Type to Choose	672
4	Sensitivity	673
4.1	Sources of Risk for Sensitivity	674
4.2	Statistical Methods for Evaluating Sensitivity	674
5	Putting It All Together: The Effect of Inadequate Measurement on the Conclusions Drawn from the Study	675
6	Conclusion and Future Directions	677
	References	678

Abstract

Measurement is central to empirical research whether observational or experimental. Common to all measurements is the systematic application of numerical value (scale) to a variable or a factor we wish to quantify. Measurement can be applied to

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663

physical, biological, or chemical attribute or to more complex factors such as human behaviors, attitudes, physical, social, or psychological characteristics or the combination of several characteristics that denote a concept. There are many reasons for the act of measurement that are relevant to health and social science disciplines: for understanding aetiology of disease or developmental processes, for evaluating programs, for monitoring progress, and for decision-making. Regardless of the specific purpose, we should aspire that our measurement be adequate. In this chapter, we review the properties that determine the adequacy of our measurement (reliability, validity, and sensitivity) and provide examples of statistical methods that are used to quantify these properties. At the concluding section, we provide examples from the physical activity and public health field in the four areas for which precise measurements are necessary illustrating how imprecise or biased scoring procedure can lead to erroneous decisions across the four major purposes of measurement.

Keywords

Measurement · Reliability · Validity · Sensitivity · Bias · Error

1 Introduction

Measurement is central to empirical research whether observational or experimental. A study of a novel, well-defined research question can fall apart due to inappropriate measurement. Measurement is defined in a variety of ways (Last 2001; Thorndike 2007; Manoj and Lingyak 2014), yet common to all definitions is the systematic application of numerical value (scale) to a variable or a factor we wish to quantify. Measurement can be applied to physical, biological, or chemical attribute or to more complex factors such as human behaviors, attitudes, physical, social, or psychological characteristics or the combination of several characteristics that denote a concept, for example, “disability” or “quality of life.” Hence, when researchers intend to measure complex or abstract concepts, the act of measurement involves two more steps prior to assigning the numerical value; first, to identify and define the quality or the attribute of the concept they wish to measure and, second, to determine the set of operations by which the attribute may be isolated (Thorndike 2007). For example, if we wish to measure people’s diet, we will first need to define “what are the qualities of the diet that we wish to measure?” Let us assume that in diet we wish to measure “eating habits.” In this case, the operationalization of this concept can be (a) pattern of eating or (b) quality of the diet. Regardless of how the concept is operationalized (a or b), each decision will be associated with breaking down the broad definition to domains that need further quantifications and a scoring system for these domains. For example, if (a), eating could be quantified by the number of meals per day, time lapse between meals, or snacking frequency, whereas “(b) quality of diet” needs to be broken down to a list of foods within domains such as “healthy food items” and “unhealthy food items.” The next decisions will relate to scoring, numerical value, of these domains. What will be the scale metric for pattern of eating? Is it a continuous

variable with values range from 1 (e.g., one episode of eating) to 24 episodes of eating (i.e., episode for every hour) whereby the higher the score, the closer to “overeating pattern.” We may also wish to give greater weight for one domain such as snacking compared to a usual meal? In short, measurement of complex concepts involves a lot of thinking and decisions to make before the development of the instrument and during the process of assigning numerical values to each item.

There are many reasons for the act of measurement. Here, we suggest four main purposes that are relevant to health and social science disciplines:

1. Aetiological – understanding relationship between attributes and determining causality
2. Evaluation – determining success or failure of programs and interventions
3. Monitoring – identifying secular changes in important factor
4. Decision-making/actions – classifying population according to norms, using score to predict an outcome

Regardless of the specific purpose, we should aspire that our measurement be adequate.

Inadequate measurement can lead to spurious conclusions about the nature of aetiological relationship, undermining or overstating the effectiveness of program/intervention, erroneous conclusions about secular trend, or misclassifying population as having health risk or not or predicting whether a person will be a successful medical school graduate.

In the following sections, we will review the properties that determine the adequacy of our measurement: reliability, validity, and sensitivity. We will use the general term “instrument” when referring to measurement properties, which could be a technological device that were designed to assess specific characteristics or behavior, survey questionnaires, laboratory tests, or human observations. We will then give examples on the effects of measurement errors on the validity of conclusions in aetiology, evaluation, monitoring, or decision-making.

2 Reliability

Reliability of the data and findings is one of the essential components of any research process. Reliability is defined as the extent to which results are consistent over repeated testing periods and an accurate representation of the study population under similar methodology (Golafshani 2003; Griffiths and Rafferty 2014). In principle, reliability deals with repeatability, consistency, reproducibility, and dependability of the result findings which are critical elements of any research (Nunan 1992; Leung 2015). The lack of reliability of an instrument will invariably affect the validity of such instrument (Bolarinwa 2015). Hence, having a reliable instrument is essential for the precision, accuracy, and adequacy of the measurement. For example, a weighing scale measuring a person’s weight cannot be considered reliable if it

provides different readings of the same person in a short period of time that is inconceivable to gain weight, and, hence, it may indicate a faulty scale.

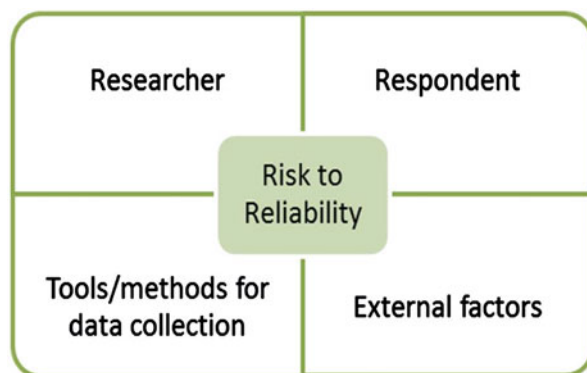
2.1 Sources of Risk for Reliability

When conducting research, it is imperative to be aware of the different conditions that endanger reliability of the findings. Any measure is subject to some degree of imprecision or error which inversely affects reliability. For example, the greater is the degree of imprecision or error, the less accurate the result findings. The errors can be at random, which is less concerning, or systematic known as biases. Brink (1993) collectively categorized the major sources of risk for reliability (biases) into four groups as seen in Fig. 1.

2.1.1 Researcher

A researcher or observer is frequently used as the instrument for data collection, and therefore, it is important to consider the source of errors associated with observer as an instrument. First, observer can produce systematic error that occurs during querying, recording, and interpreting of the data commonly known as “observer bias” (Pannucci and Wilkins 2010). Therefore, an observer’s knowledge of the hypothesis, disease, or exposure status contributes to bias with varying levels of misclassification, which in turn affects the reliability of the study findings (Delgado-Rodríguez and Llorca 2004). This may not always be deliberate but may involve subtle changes in the way the interviewer interacts and chooses to put emphases on selective questions (Davis et al. 2009). For example, if the interviewer is aware that the patient has lung cancer, he/she may put more emphasis on certain questions (“Are you sure you’ve never smoked? Never? Not even once?”), among cases prompting answers toward one direction (smoking) in cases but not in controls, leading to differential bias.

Fig. 1 Validity source dilemma – a purpose-led approach is here



2.1.2 Respondent

Reliability of the source is directly associated with the quality of research. The accuracy of information received from respondent is a key concern when responses are collected via interviews and questionnaires. Bias may be introduced when respondents try to provide information better or worse than they really are (Delgado-Rodríguez and Llorca 2004). Participants might also be less reliable, being hesitant and deliberately withholding some critical information, known as social desirability bias. In other cases, participants may find cognitive difficulties to reconstruct information from the past, what is known as recall bias. For example, patients are more likely to recall their medical and treatment history associated with an exposure compared to people who are free of disease and selected as comparison group.

2.1.3 Tools/Methods for Data Collection

As aforementioned, research instruments could be in the form of interviewer, questionnaires, or measurement devices. Accuracy in measurement is crucial, and, therefore, for an instrument to be reliable, it has to repeatedly measure what it is supposed to measure in a consistent manner (Leung 2015). In addition to researcher and participants' biases, measurement errors due to methods of data collection can affect reliability. For example, faulty devices (e.g., timeworn, broken) can produce inconsistent reading. Tools that are not calibrated can introduce bias to readings, either systematically over- or underestimation of the accurate value. Therefore, it is important to conduct regularly calibration of instruments by pretesting or pilot testing against a standard value in order to identify and minimize such errors (Kimberlin and Winetrstein 2008).

2.1.4 External Factors

External factors, such as environmental and social context in which the research is carried out, also influence the degree of reliability. First, mechanical devices can be sensitive to extreme weather conditions, such as extreme heat or coldness, hence affecting the consistency of the reading in comparing to "normal" conditions. If the measurement is conducted by humans under extreme weather conditions, they may not have the same concentration level or energy to perform the measurement. Participants may also exhibit different behaviors under different social environments. For example, patients may not provide sensitive information when they are in a group, whereas they are likely to reveal this information in a more solitary environment (Brink 1993).

Similarly, gender and cultural differences between researcher and respondents may also affect the reliability of result findings. For example, women would be more likely to withhold information on their sexual activity or breastfeeding activity in the presence of a male interviewer. Ursachi and colleagues (2015) examined the reliability of three instruments used in market research and have shown that the reliability coefficients of each instrument varied by socioeconomic factors, rural or urban residency, and degree of religiosity.

2.2 Types of Reliability and Their Associated Statistical Methods

Although it is not feasible to provide an exact measure of reliability, different measures can be used to achieve an estimate of reliability. There are three general estimators of reliability which are as follows:

1. *Inter-rater or interobserver reliability* – This test is used to establish the level of agreement between different instruments or between two or more observers measuring the same factor (Heale and Twycross 2015). The inter-rater reliability determines the equivalence of the measures. For example, consistent readings obtained from two different sphygmomanometers measuring a person's blood pressure relates to a good level of inter-rater reliability of the instruments. Inter-rater reliability can be assessed by statistical methods such as the Cronbach's α test for quantitative measures and Cohen's kappa statistic for categorical measures (Bowling and Ebrahim 2005).
2. *Test-retest reliability* – This form is used to assess the consistency (AKA stability) of a measure over time (Griffiths and Rafferty 2014). Test-retest reliability requires using the instrument (say a questionnaire on attitudes, knowledge, or behavior) on the same sample population at two different time periods and comparing the scores for consistency. It is important to note that the two time periods should be within the timeframe of the recall period. For example, if a questionnaire queries about past week behavior, the test-retest should be undertaken within the same week that the behavior is recalled. It is important to note that test-retest reliability for activities that change from day to day is not recommended for factors that changes over a short period of time. For example, the frequency and duration of walking to do errands may change from one day to the other. Hence, if you ask to recall walking trips of the past week, the repeatability may be reduced because it is hard to recall this behavior over a week. It is preferable to ask about walking for errands in the past 24 h to increase accuracy, but then the retest should be within the same day. Statistics such as Cohen's kappa coefficient (for dichotomous scale) and Pearson's correlation (for continuous scale) or Spearman rank correlation (for scale that is not normally distributed) can be used to quantify the test-retest reliability (Manoj and Lingyak 2014). In general, a test-retest correlation of 0.70 is acceptable, 0.80 is good, and 0.90 is excellent (Manoj and Lingyak 2014).
3. *Internal consistency reliability* – This test measures the extent to which each item in the instrument is related to other items (Manoj and Lingyak 2014), in simple words, the degree to which items are held together. Internal consistency determines the homogeneity of the measures. Essential requirement is that the scale has more than one item that measures the phenomenon. There are three primary approaches to estimate internal consistency: Cronbach's α , Kuder-Richardson coefficient, and split-half reliability (Manoj and Lingyak 2014). Regardless of methods, all values range from 0 to 1, with values closer to 1 represent strong correlation and, hence, high reliability of the instrument and vice versa. Cronbach's α is the most commonly employed method to evaluate the internal

consistency of an instrument. It takes the mean of the individual item-to-item correlations and adjusting for the total items in the instrument. Some classifications of reliability estimates were offered: coefficient below 0.6 is considered unacceptable, 0.6–0.65 is undesirable, whereas correlations range between 0.7 and 0.9 are acceptable, good, or excellent (0.8–0.9). It is also suggested that if a coefficient is too high (>0.9), there is a possibility that some items may not be necessary and the scale can be shortened (Manoj and Lingyak 2014).

In split-half reliability, the result findings of an instrument or test are split into two equal halves (e.g., either by random selection, odd and even numbered, or first and second half), followed by calculating the correlations using by Spearman-Brown split-half reliability methods and comparing the correlation across both halves and to the entire test (Manoj and Lingyak 2014; Heale and Twycross 2015). A drawback of this method is that the reliability will vary depending on the methods of splitting chosen (Manoj and Lingyak 2014). The Kuder-Richardson test is a variant of split-half method and is appropriate for a scale that consists of dichotomous responses such as true/false or yes/no and alike. Another method, not so much in use, is the item-to-total correlation test, which is performed to find the relationship between each item with the total scale, thus eliminating inconsistent items before determining factors that represent the construct. A correlation value less than 0.2 suggests that the corresponding item does not correlate with the overall scale, whereas high inter-item correlations (>0.8) indicate the presence of repetitions which should be removed (Streiner and Norman 2003).

3 Validity

All measurements require validity evidence. Validity answers the question whether the instrument measures what it requires to do. Unlike reliability, which is an attribute of the instrument, validity is not an attribute but rather the extent of support for interpretation of scores on an instrument when it is being used for its intended purpose. When we carried out a measurement and we ask “how valid is it,” we are inquiring whether the instrument measures what we want to measure, all of what we want to measure and nothing but what we want to measure (Thorndike 2007).

Validation research uses theory, data, and logic to argue for or against specific score interpretations: “validity is always approached by hypothesis, such that the desired interpretative meaning associated with assessment data is first hypothesized and then data are collected and assembled to support or refute the validity hypothesis” (Downing 2003, p. 830). It is agreed that assessment data for validity study are more or less valid for some very specific purpose, meaning, or interpretation, at a given point in time and only for some well-defined population (Downing 2003; Schmidt and Bullinger 2003). This may explain why, for example, one questionnaire has been validated repeatedly in different populations and presented a range of coefficients.

Several varieties are distinguished as though they established different “types” of validity, which can be confusing “am I using the correct name for the type of validity study?” For example, accelerometer is used to validate physical activity questionnaires,

but some researchers refer to this source as “criterion validity” and others as “construct validity;” which one is the correct term? In general, there are three main types: content validity, construct validity, and criterion validity. Other terms such as “face validity,” “convergent validity,” “concurrent validity,” and “predictive validity” are also in use, but these may be considered as sub-type within the three main types.

3.1 Types of Validity Evidence and Their Associated Statistical Methods

Content validity – this source of evidence answers the question “to what extent the content of the instrument incorporates the phenomenon under study.” For example, complex constructs such as “functional health” can be assessed by questionnaire, but the instruments should grasp several domains such as activity of daily living and occupational, family, and social functioning. The developers of the instrument are best placed to provide the rationale of the domains used to measure the phenomenon and why these items were selected to represent each domain. But the judgment about the plausibility of the rationale should be made by others known as “experts.” Content –related evidence involves several steps:

- (a) The process by which the instrument was developed (e.g., panel of experts, consultation with users). Grant and Davis (1997) present important consideration for how to select experts and how to utilize the information they provide.
- (b) Provision of a clear, explicit statement (definition) of what is being measured, referred to by Thorndike (2007) as “blueprint” and table of specification, which is the specification of the content to be covered in the instrument. This needs to include full account for whether the instrument omits important elements or included irrelevant ones.
- (c) The plausibility of the explicit or implicit rationale linking the content of the instrument to the definition of what it is to be measured.
- (d) Provide evidence for the acceptability of instrument by the target population; it is of no use to have a rationale and good coverage of the construct if the participants are not able to provide the answers.

The methods of quantifying experts’ agreement are qualitative in nature, and this is where the term “face validity” takes place. This is the most basic type of validity of the instrument; it means that the experts think that the item appears to measure the construct under consideration; be appropriate for assessing this concept in the target population on the “face” of things. The panel, for example, is sent the “blueprint” of the instrument with instruction to determine the face validity and the content validity of the operational definitions of each variable within each domain that form the whole instrument. This forms the first draft of the instrument. Their comments on the first draft lead to the second draft with the aim to reach a consensus among panel members. The instrument is finalized when consensus is reached.

Construct validity – this source of validity investigates the extent to which the items of the instrument correspond to the phenomenon under the study overall and

how well they related to each other. A simple example from health science would be, if on theoretical grounds, the phenomenon should change with age, a measurement with construct validity should reflect such change. Construct validity also answers whether there is a logical structure of the instrument and whether the items measure a unidimensional construct or a multidimensional construct. An example from the field of psychology would be an instrument that was developed to measure a trait such as “motivation to achieve;” this instrument should correlate with college grades and with completion of more items on a speeded test, given the ability being equal. If these predictions are met, we can say the instrument measured meaningfully the “construct motivation to achieve” (Thorndike 2007). A statistical approach to measuring construct validity is confirmatory factor analysis, which is a complex method that is used for construct validation. It tests whether the number of factors/domains and their loading on indicator variables conform to what we expect based on theory or hypothesis. Indicator variables are selected based on pre-established theory. For example, the concept “walkability” refers to features of the environment that encourage/or discourage (if absent) walking by residents. Researchers have used confirmatory factor analysis to develop a questionnaire measuring the perception of walkability, and these factors should correlate with the level of walking. This long instrument was abbreviated, and confirmatory factor analysis was used to test whether the abbreviated version retains similar factors (Cerin et al. 2006). More details on the technicality of factor analysis and sample size can be found in Manoj and Lingyak (2014, pp. 127–141). One sub-type of construct validity is “convergent validity” which is often used to compare two different instruments measuring the same construct. For example, two measures that assess quality of life are compared; theoretically they should be related to each other, but by how much?

Criterion validity – the extent to which the instrument correlate with an external criterion of the phenomenon under study. Criterion is often considered “a gold standard” of the phenomenon. For example, a visual inspection of a wound for evidence of infection can be validated against bacteriological examination of the wound, which is the “gold standard” criterion that is used to validate doctors’ judgment. However, in social science, validation against a criterion is not that straightforward. Some behavior has no clear “gold standard.” Thorndike (2007) further explains that criterion needs to fulfill four qualities: it has to be relevance, free from bias, reliable, and available. For example, fitness test is often considered as a criterion against scores produced by self-reported physical activity questionnaires. According to theory, a person who is regularly active is expected to achieve a better cardiorespiratory fitness score than a person who less is frequently active, yet genetics can also play a role in explaining high fitness test even if a person does not exercise at all. Therefore, it cannot be accepted as a “gold standard.” Fitness test, however, is an objective physiological measure of cardiorespiratory fitness, and, therefore, it is free from common biases of self-report instruments that involve recall or social desirability biases, which reduce their accuracy. Fitness test is also a stable measure, unless a person purposefully engaged in intervention to improve fitness, the results of one test over time are expected to be the same under similar laboratory

condition, and the test is accessible and reasonably cheap. This makes fitness test a good criterion for validation of self-reported questionnaire.

There are two broad classes of criterion-related validity (Last 2001):

- (a) Concurrent validity – this examines the correlation between two instruments that supposedly measure the same thing and the scores are obtained concurrently (at the same time). Self-report consumption of surgery food in the past 24 h is compared to sugar level in the blood in the same day.
- (b) Predictive validity – this is when performance on one instrument is used to forecast the performance in the future, for example, relationship between scores on a college admissions test and subsequent grades in college.

The statistical methods that are used for concurrent validity produce correlation coefficients (r); it can be Pearson coefficient or, if data is not normally distribute, the Spearman rho coefficient. If the predictive validity is sought, a regression equation can be computed, which tells us what our “best guess” of a person’s score on the criterion would be, given the person’s score on the predictor instrument (Thorndike 2007).

3.2 Which Validation Type to Choose

Current view is that construct validity encompasses all evidence and rationales for supporting trustworthiness of score interpretations. A key feature is that there is some organizing theoretical or conceptual framework to serve as a guide to score interpretation. If the construct validity is “the whole validity,” why do we need content and criterion validity? In the context of social science, primarily education, Downing (2003) argues that validity is a unitary concept, with construct validity as the whole of validity, but has five related units: content, response process, internal structure, relationship to other variables, and consequences. This means that all other types of validity sit under construct validity. Thorndike (2007) views content and construct validity as “interpretive inference” and criterion validity as an “action inference” and argues that every instrument requires both. This means that ideally all sort of validity evidence should be provided. Here, we present a more pragmatic view that focuses on the purpose of the study as depicted in Fig. 2.

Ideally, researchers would like to present all sources of validity for a particular instrument, but there are some that will be most important and other less, dependent on the context or purpose of their research. In case researchers wish to develop a new instrument from scratch, they must present face and content validity of their instrument following by construct validity. If researchers wish to adapt existing instrument to other population or to create an abbreviated version of already existing instrument, it is good to present face or content validity of the adapted/abbreviated version (e.g., cultural aspects that were not addressed in the existing instrument), but not less important is to conduct construct validity to justify retention or removal of certain items. Some good example of instruments of quality of life in abbreviated or long

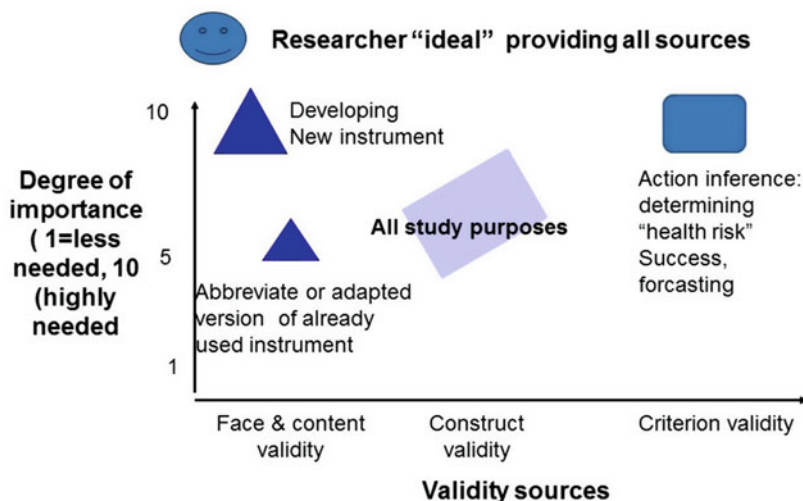


Fig. 2 Different sources of errors that risk the reliability of an instrument is here

form can be found in the paper by Busija and colleagues (2011) with data on validity sources. When the purpose of the study is to action based on the score of an instrument (e.g., classification of “health risk,” “likely to succeed in job,” or meeting certain benchmark) most important is to demonstrate a criterion validity, although it will add value if the construct validity of the instrument is provided to enhance the theoretical support behind the criterion validity.

4 Sensitivity

Sensitivity of an instrument is of the most essential measurement property to examine in the context of intervention, because the lack of sensitivity of the instrument measuring the main outcomes may result in wrong conclusion about efficacy/effectiveness of the intervention. Although the term “sensitivity to change” is often used interchangeably with “responsiveness,” they can be distinguished as two separate entities (Walters 2009). Sensitivity is the ability of an instrument to detect changes between groups, for instance, between two groups in a clinical controlled trial (Fok and Henry 2015). In terms of experimental research, an instrument is reported to be sensitive only if it can identify clinically significant changes between and within patients over time (Gadotti et al. 2006). In addition, the instrument must show changes in the variable being assessed while being unaffected by changes in other variables under study, for example, in the comparison group that received no intervention (Deyo and Centor 1986).

Responsiveness on the other hand consists of two aspects: internal and external. The widely used internal responsiveness refers to the ability to accurately detect

small but clinically significant or meaningful changes in a phenomenon or concept being measured over time (De Bruin et al. 1997; Terwee et al. 2003). On the other hand, the external responsiveness refers to the extent to which changes in a measure over time relate to corresponding changes in a reference measure of health status (Husted et al. 2000). For example, a study conducted to measure the responsiveness of the Lachman test to detect knee improvement in patients after ligament reconstruction surgery, test from before and after the surgery showed significant changes (improvement in knee function) that suggests this test is responsive (Gadotti et al. 2006). External responsiveness differs from internal responsiveness in that, measure is not in and of itself a primary interest but a relationship between change in the measure and the change in the external standard used as reference (Husted et al. 2000).

4.1 Sources of Risk for Sensitivity

Similar to reliability, the potential sources of risk for sensitivity of instruments could be in the form of faulty devices which are either timeworn or insensitive to detect changes over time or under different conditions (e.g., temperature, air pressure). For example, if a device is designed to detect improvement in plasma glucose concentration, implementation of the scale must be effective both in the ICU and in a self-management setting. It is considered to be poorly sensitive if it is not responsive to detect changes in both the settings. In addition, wrong use of research instruments which are not specific to measure a particular variable under study could also contribute to failure of responding to changes. Thus, it is imperative to conduct repeated testing of instruments against an evidence-based gold standard device in order to verify its responsiveness (Kimberlin and Winetrstein 2008).

4.2 Statistical Methods for Evaluating Sensitivity

While sensitivity can be determined by cross-sectional studies, responsiveness can only be assessed in longitudinal design, whether experimental design comparing efficacy of a treatment (intervention) to nontreatment group, or in observational studies where medical treatments are carried out on patients over a period of time (Revicki et al. 2008).

There are various statistical methods that can be used to evaluate sensitivity and responsiveness. There are as follows:

1. *Paired t-test*: This test statistic is used to calculate the changes in the scores by an instrument over two time points (Walters 2009). This test exclusively relates to the statistical significance of the observed change in the scores, which in turn is dependent upon sample size and variability of the measure (Husted et al. 2000).
2. *Effect size*: This test has been widely employed as a method for evaluating responsiveness. In contrast to paired t-test, this test measures the magnitude of

change in the measure by the standard deviation of the baseline measure of the instrument (Walters 2009).

3. *Standardized response mean (SRM)*: This test is a measure of ratio of magnitude of changes and the standard deviation reflecting the variability of the change scores (Husted et al. 2000).

In addition to the abovementioned methods, other methods such as repeated measures analysis of variance, responsive coefficient, Guyatt's responsive statistic, receiver operating characteristic curves, and regression models are also used (Deyo et al. 1991; Terwee et al. 2003).

5 Putting It All Together: The Effect of Inadequate Measurement on the Conclusions Drawn from the Study

In this section, we would like to present few examples where study conclusions were erroneous or compromised due to measurement issues. We will review examples from the physical activity and public health field in the four areas for which precise measurement is necessary: aetiology, evaluation of intervention, monitoring, and decision-making.

Aetiology: Epidemiological studies involve thousands of people at the minimum; therefore, self-report questionnaires are the most practical available method to measure complex behaviors such as diet or physical activity, both are established risk factors of many chronic diseases. One interesting question that occupied physical activity epidemiologists since the early 1990s is whether physical activity must be at high intensity to gain health benefits or lower intensities are also health enhancing. An epidemiological study by Yu et al. published in 2003 entitled "What level of physical activity intensity protects against premature cardiovascular death?" was one of several others that assessed this question. The researchers used the Minnesota Physical activity questionnaire which had excellent test-retest repeatability (0.88–0.82) and good concurrent validity (0.33–0.58) or construct validity (coefficient with fitness test 0.48). The investigators found that only vigorous-intensity leisure-time physical activity and not moderate or light intensity protected against premature mortality (Yu et al. 2003). This finding was inconsistent with all other longitudinal studies which consistently found that moderate-intensity leisure-time physical activity protected against coronary heart disease, stroke, and cardiovascular disease mortality. A careful examination of the methods described in this published paper indicated that the operationalization of intensity levels for each leisure-time physical activity deviated from the common acceptable intensity category level: light intensity included activities that raise the body energy expenditure from 2.5 up to 4 times above the resting metabolic rate, whereas moderate-intensity range is classified at 3 times and up to 6 times above rest including walking for exercise. At that study, swimming was classified as vigorous-intensity physical activity, like jogging or running, when it is usually classified at the top range of moderate-intensity level. It is most likely that the operationalization of intensity levels created systematic misclassification of the population according to

intensity level; in some participants, efforts were underestimated, and in others (like the swimmers), efforts were overestimated leading to biased conclusion that moderate-intensity exercise has no benefit. This is an example how researchers' view affects their conclusion leading to them being inconsistent with 90% of the epidemiological studies.

Evaluation of interventions: In the past two decades, the increasing trends toward a sedentary lifestyle have brought the specific behavior of walking to public health attention. Walking is characterized by its both voluntary (incidental) and intentional nature and, as such, poses a great measurement challenge (Merom and Korycinski 2017). People may be able to recall well their walking as a form of exercise (planned walks) but less likely to recall incidental walking. This is why the repeatability coefficients of walking questions are varied according to what is asked. For example, a question that assesses all source of walking, for travel and for exercise, such as in the Active Australia questionnaire, a moderate repeatability coefficient (0.53) was noted, compared with a very good (0.78) coefficient for a question that assesses only walking to get fit or exercise, such as is in the Australia National Health Survey (Brown et al. 2004). This lack of stability leads to high variance around the mean estimate and poses a great challenge in the evaluation of the effect of walking promotion. In the evaluation of the step-by-step walking promotion, Merom et al. (2007) used several measures; one was the Active Australia walking question; one was the Harvard Alumni leisure-time physical activity questionnaire which asked about any planned recreational or exercise activities of the past 3 months, including walking; and a pedometer step count. A definitive effect was seen only for the pedometer step counts and the Harvard Alumni questions but none on the Active Australia walking question (Merom et al. 2007). It is now very common to use objective measures of physical activity along with self-report questionnaire in order to prove effectiveness of walking interventions due to the large measurement errors of the self-reported questions (Harris et al. 2016).

Monitoring: Physical activity is an important behavior to monitor due to its health-enhancing potential. The most important requirement of effective monitoring is to keep the instrument exactly the same as the baseline measurement; otherwise the changes over time will be contaminated. People may interpret differently the wording of the new question or will be asked to recall differently the amount of physical activity which will not be comparable with the old version. For example, positive change toward increased physical activity levels was reported in the UK over a 15-year period, but the authors alerted the readers that the walking question within the National Health Survey was changed in the middle of the period and included walking for everyday purposes (Stamatakis et al. 2007). Merom et al. (2007) also reported a biased estimate of walking trend over time which could be due to increased population's awareness of messages about the health-enhancing potential of everyday walking. For example, when Australians were asked to report on all types of exercise, recreation, or sports activities that they did in the past 12 months, the major increase was noted in walking behavior. The question is whether this was a real increase or a biased finding? A content analysis of what Australians consider as recreational, sport, and exercise walking revealed that about 4% of responders considered travel-related walking as part of exercise. These

changes in perception may explain the increasing trend – while the behavior of walking for exercise remains the same, it is possible that the responders now perceived travel-related walking as exercise when previously they would not do so (Merom et al. 2009).

Decision-making: Health professionals often make decision by rough classification of individuals into categories that predict risk of disease. For example, obesity is considered at a body mass index equivalent to 30 and overweight at 25. Similarly, population is classified as “physically inactive” when they failed to reach the minimal recommendations for health. However, physical activity screening used by general practitioners (GPs) is a poor proxy of human movement. Primary care physical activity initiatives (e.g., the SNAP, the Lifescript, the Australian Better Health Initiatives) utilize a short self-report questionnaire to identify inactive clients, but individual-level inference from questionnaires is problematic due to large error margins. The predictive validity of the (1) “Lifescript” questionnaire administered by GPs, (2) a GP’s own assessment methods, and (3) patients’ step count using a pedometer were compared against accelerometer criterion of ≥ 30 min of moderate-to-vigorous physical activity. Pedometer had the highest accuracy, 82% sensitivity and 100% specificity, using 7500 steps per day as a criterion for active individuals. GPs’ subjective assessments performed better than the self-reported questionnaire (Winzenberg and Shaw 2011). At the population level, there will be large discrepancy between estimates of the prevalence of physically inactive adults if the classification is based on questionnaire or accelerometers (50% vs. 12%, respectively) or if researchers use the same self-reported questionnaire but the operationalization of the scoring system to derive the cut point for “physical inactivity” differs (Brownson et al. 2000).

6 Conclusion and Future Directions

Good measurement skills are fundamental to research and practice. The quality of the knowledge base and the decisional process that follows the advancement in knowledge are all influenced by the precisions of the instruments that are in use. Therefore, the art of improving the measurement properties is everlasting and under examination for proper reasons. In public health and social science, the information gathered typically rely on large number of people at different points of time; hence, self-reported questionnaires are the most cost-saving and practical solution. Therefore several issues need to be considered: (1) how much information can we include in the questionnaire without posing too much burden that can lead to missing of answers due to the burden and (2) should we include information that is cognitively challenging (i.e., very difficult to remember or quantify) on account of reducing the accuracy of the response, that is, reducing the reliability? The balance between the amount of information sought and the risk to the measurement properties of the questionnaire will always need to be considered. More questions to increase content validity may compromise measurement properties. The rapid advancement in technology and the reduction in cost of the new technologies suggest that new devices will always be introduced to the market. Hence, previous information derived from

older versions may not be equivalent to the new information generated from the state-of-the-art devices. Researchers and practitioners must be aware of the model they use, year of production, and how to adjust the new values to the old versions. Finally, in this chapter, we cover only few statistical methods as examples. This may change profoundly according to type of variable scales, whether it is a binary variable, categorical variable with a nominal or ordinal scale, or continuous variable. The way the data is manipulated and its distribution will determine the statistical methods, and this was out of the scope of this chapter.

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Integrated Methods in Research

39

Graciela Tonon

Contents

1	Introduction	682
2	Triangulation	683
3	Mixed Methods	683
4	Conceptualizing the Term “Integration”	685
5	The Role of the Researcher in the Integration of Research Methods	687
6	Innovation and the Use of New Technologies for Integrated Methods in Research	688
7	Recommendations for Research Projects Utilizing Integrated Methods	689
8	Conclusion and Future Directions	690
	References	691

Abstract

The process of integration of methods in research is not without its difficulties. In some cases, the literature does not specify the differences between triangulation, mixed methods, and integrated methods. The integration of methods in research springs from triangulation, as far as the validation process of the completed research is concerned, and converges in the use of mixed methods as a strategy to complement and expand the combination of the quantitative and qualitative methods. This chapter aims to promote integration based on the notion that it can be achieved if the researcher thinks in a holistic way from the outset of the research process. An integrated methods study first requires the researcher to consider quantitative and qualitative methods in a way that does not result in contradictions, as both methods should collaborate with and complement each

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681

other in pursuit of a common aim. This is only possible where the researcher adopts an open and creative stance and avoids extreme positions. Finally, these considerations allow us to conclude that the integration of methods in research is a form of innovation.

Keywords

Research methods · Integration · Innovation · Triangulation · Mixed methods

1 Introduction

This chapter discusses the concepts and use of integrated methods in health social science research starting from the consideration that integration is a systemic process whose complexity lies in the relationships between the dimensions it involves (Grbich 2017). In this sense the combination of different individual elements is what makes up a coherent whole when they are brought together. The lack of integration is problematic in studies where greater understanding or more valid results might have been obtained if all types of available data had been considered together (Bazeley 2009), so we propose the use of integration of methods in health social science research to achieve a holistic and deeper analysis of the data generated in the studies.

For a proper discussion of integrated methods in research, it is necessary to discuss three considerations: the distinction between qualitative and quantitative methods, the review of the definitions of the concepts of triangulation and mixed methods, and the role of the researcher and the possibility of considering integration as a kind of innovation.

First and considering the distinction between qualitative and quantitative methods (see also ► Chap. 63, “Mind Maps in Qualitative Research”), we will remember Huston (2005) when he says that this distinction was really between variable-oriented and person-oriented approaches. Maxwell (2010, p. 477) argues that “the distinction between qualitative and quantitative is the distinction between thinking of the world in terms of variables and correlations and in terms of events and processes.” Jones and Summer (2007, p. 5) remind us that the terms qualitative and quantitative are used to refer to:

types of methodology – the overall research strategy used to address the research questions or hypotheses; types of methods of data collection – i.e. the specific methods; types of data collected – i.e. the raw data; types of data analysis – i.e. the techniques of analysis; and types of data output – i.e. the data in the final report or study.

Second it is necessary to review the definitions of the concepts of triangulation and mixed methods, as in some cases the term “triangulation” has been used interchangeably with “mixed methods” or “integration of methods.” This has created some problems as it has obscured the difference between “the processes by which methods (or data) are brought into relationships with each other (combined, integrated, mixed) and the claims made for the epistemological status of the resulting knowledge” (Moran-Ellis et al. 2006, p. 2). In addition, it has blurred the distinction between the outcomes and the process.

Third, the chapter goes on in the conceptualization of the term integration by making a reflection on the role of the researcher and proposing recommendations for research projects utilizing integrated methods which lead to the possibility of considering integration as a kind of innovation.

2 Triangulation

A brief historical review of the concept of triangulation shows that in its origins, much emphasis was placed on increasing confidence in the results obtained. This was referred to by various authors as *increasing validity* (Campbell and Fiske 1956; Webb et al. 1966; Fielding and Fielding 1986). Some years later, other authors (Lincoln and Guba 1985; Smith and Hershuisius 1986) adopted a different approach according to which “methods can be triangulated to reveal the different dimensions of a phenomenon and to enrich understandings of the multi-faceted complex nature of the social world” (Moran-Ellis et al. 2006, p. 6).

Prior to that, Denzin (1978) had already defined triangulation as the combination of methodologies for the study of the same phenomenon. Jick (1979, quoted in Tonon 2015) outlined some of the advantages of using triangulation, namely, that it allowed researchers to be more confident of their results and it stimulated the development of creative forms of gathering data and facilitated the synthesis of theories as well as the contemplation of contradictions.

Kelle (2001) presents the term “triangulation” taking into account that many authors consider it as a central concept for method integration. The author states that “this notion carries systematic ambiguities, at least when transferred to the integration of qualitative and quantitative methods – triangulation does not represent a single integrated methodological concept but a metaphor with a broad semantic field” (Kelle 2001, p. 1). Finally, Kelle distinguishes between three types of triangulation: as mutual validation, as the integration of different perspectives on the investigated phenomenon, and in its original trigonometrical meaning.

According to Creswell et al. (2004), research studies using triangulation typically organize separate sections for each of the methods (quantitative and qualitative), so that one section deals with data collection and quantitative analysis, while the other contains a discussion of the data collection and a qualitative analysis. In the final section, the researchers discuss the results of both analyses. This leads us to conclude that the term triangulation has been, and is still, used to indicate the use of more than one method in a research process.

3 Mixed Methods

In 2002, Sale, Lohfeld and Brazil published an article on the combination of quantitative and qualitative methods in health studies. The authors, following Guba (1990, p. 18), argue that each of these methods is based on a particular paradigm, a patterned set of assumptions concerning reality (ontology), knowledge of that reality (epistemology), and the particular ways of knowing that reality

(methodology) (see also ► [Chap. 6, “Ontology and Epistemology”](#)). The authors, thus, state that each of these methods does not study the same phenomenon and propose a new solution for using mixed methods in research. They further argue that the distinction of phenomena in mixed methods research is crucial and can be clarified by labeling the phenomenon examined by each method, rather than merely using the strengths of each method to notice the weaknesses of the other, or capturing various aspects of the same phenomena. They finally propose carrying out each method simultaneously or sequentially in a single study or series of investigations.

Prior to that study, in the field of nursing research, Shih (1998, p. 633) had pointed out that the “analytic density” rationale does not mix methods to obtain more reliable and valid findings but to get a wider and deeper picture from all angles (quoted in Fielding 2012, p. 127).

Pawson (1995 quoted by Moran-Ellis et al. 2006, p. 13) criticizes multiple methods and data approaches which primarily generate more data about a phenomenon without addressing how the plurality of data will be combined analytically. Sandelowski et al. (2009) discuss the nature of data and quote Wolcott (1994, pp. 3–4) when he argues that “[e]verything has the potential to be data, but nothing *becomes* (italics in the original) data without the intervention of a researcher who takes note – and often makes note – of some things to the exclusion of others.” Punch (2005, p. 246) identifies three important factors for the use of mixed methods: whether the methods are taken as equal, whether or not they influence the operationalization of each other, and whether they are conducted simultaneously or analytically.

Fielding (2012) summarizes the work of Ivankova and Kawamura (2010), which consisted in an extensive bibliometric survey of mixed methods practice. On the basis of searches of five databases (PubMed, ERIC, PsychInfo, Academic OneFile, Academic Search Premier) and two journals (Journal of Mixed Methods Research, International Journal of Multiple Research Approaches), the authors found a consistent growth in mixed methods research since 2000, from $N = 10$ (2000) to $N = 243$ (2008).

Johnson and Onwuegbuzie (2004) argue that mixed methods are plural and complementary, allowing the researcher to adopt an eclectic approach. In a subsequent writing, Johnson et al. (2007) define mixed methods as an approach to theoretical and practical knowledge that takes into consideration multiple points of view, perspectives, positions, and outlooks, both at a qualitative and quantitative level. Along these lines, Maxwell (2010, p. 478) warns us that:

the use of numbers per se, in conjunction with qualitative methods and data, does not make a study mixed-method research.....the systematic (although not necessarily explicit) use of both ways of thinking is what is most distinctive of, and valuable in, mixed-method research.

In addition, according to Greene (2007), the value of mixed methods research is in creating a dialogue between different ways of seeing, interpreting, and knowing, not simply in combining different methods and types of data. This leads us to agree with Creswell (2018) when he points out that a mixed methods design is useful to capture the best of both quantitative and qualitative approaches (see also the ► [Chaps. 4, “The Nature of Mixed Methods Research,”](#) and ► [40, “The Use of Mixed Methods in Research”](#)).

4 Conceptualizing the Term “Integration”

The term “integration,” first defined in an article published in the 1981 issue of the ECLAC (UN) Review, arises from the confluence of the fields of economics and politics. The author of the article, Cohen Orantes (1981), points to the need to conceive integration as a process deriving from a set of activities taking place in a continuous manner, aimed at intensifying interdependence between its elements (participants) for the achievement of mutual benefits.

Based on this definition, we start from the premise that integration involves the combination of different individual elements that make up a coherent whole when they are brought together. In the field of research methods, according to Moran-Ellis et al. (2006, p. 3) “integration in multi methods/multi data research must be understood as a particular practical relationship between different methods, sets of data, analytic findings or perspectives.”

Integration has been variously described as being undertheorized and understudied (Greene 2007, cited in Bazeley and Kemp 2012, p. 55). The lack of integration is problematic in studies where greater understanding or more valid results might have been obtained if all types of available data had been considered together (Bazeley 2009). Bazeley and Kemp (2012, p. 56) remark that “not only is integration of methods undertheorized and understudied but also the level of integration practiced in many mixed methods studies remains underdeveloped.” Other authors have considered several forms of integration, such as separate methods and integrated analysis (Bazeley 2002; Moran-Ellis et al. 2004) and separate methods, separate analysis, and theoretical integration (Green 2003).

Bazeley and Kemp (2012) examine the metaphors used to describe the process of integration of analyses in mixed methods research, discovering different ways in which researchers think and write about integration. The authors conclude their analysis by identifying principles that guide the effective integration of analyses in mixed methods research, among which they highlight the following: there are different ways to integrate data; integration might begin at any stage within a study; integration needs to occur before conclusions, crucially during analysis or during the analytic writing of results; the level of integration must be appropriate to the goals and purposes of the study; the product of the integration must be such that it would not have been available without that integration; finally, an integrated study should not be written up as separated components, as this is antithetical to the concept of interdependence (Bazeley and Kemp 2012).

Pawson (1995, quoted in Moran-Ellis et al. 2006) refers to the work of integration as *synthesis*, which includes preplanning, the maintenance of the modalities of the different types of data while at the same time dissolving barriers among them. The methods thus interface and enmesh with each other.

Bryman (2006) has published an important article in which he studied how quantitative and qualitative research is integrated and combined in practice. The article is based on a content analysis of 232 social science articles. His examination of the research methods and research designs employed suggested that on the quantitative side, structured interview and questionnaire research within a cross-

sectional design tends to predominate, while on the qualitative side, the semi-structured interview within a cross-sectional design tends to predominate. His research reported that there is considerable value in examining both the rationales that are given for combining quantitative and qualitative research and the ways in which they are combined in practice but that it is important to recognize that when concrete examples of research are examined, there may be a disjuncture between the two.

In addition, Bryman (2007) refers to the so-called genuine integration by discussing how the components of mixed methods research are effectively integrated. In his article, Bryman reports the findings of a study in which he interviewed 20 UK researchers that worked with mixed methods. He identified different types of barriers to the integration of findings in mixed methods research and the factors that hinder the capacity of researchers to engage in such integration, pointing out that “the key issue is whether in a mixed methods project, the end product is more than the sum of the individual quantitative and qualitative parts” (Bryman 2007, p. 8).

In the field of health services research, Fetters, Curry and Creswell (2013) examine the key integration principles and practices in mixed methods research and point out that the extent to which mixed methods studies implement integration remains limited. Fetters and colleagues identify different levels of integration in mixed methods studies: integration at the design level, at the methods level, at the interpretation level, and at the level of reporting the findings. Integration at the methods level can occur through connecting, building, merging, and embedding. Integration through connecting occurs when one type of data links with the other through the sampling frame. Integration through building occurs when results from one data collection procedure inform the data collection approach of the other procedure, the latter building on the former. Integration through merging of data occurs when researchers bring the two databases together for analysis and for comparison. Integration through embedding occurs when data collection and analysis are being linked at multiple points and is especially important in interventional advanced designs, but it can also occur in other designs. Finally, the authors point to the existence of the fit of data integration, which refers to the coherence of the quantitative and qualitative findings, and state that the assessment of the fit of integration leads to three possible outcomes: confirmation, expansion, and discordance.

The combination of different methodologies and interpretive approaches does not necessarily enhance validity but can extend the scope and depth of understanding (Fielding and Fielding 1986; Fielding and Schreier 2001; Denzin and Lincoln 2005; Fielding 2012). For Fielding (2012), integration is the heart of the whole mixed methods exercise because the purpose of mixing methods is to get information from multiple sources and so the issues in bringing together the information are crucial. It is not so much the stage when integration occurs but additionally what types of data are being integrated and how we integrate them (Fielding 2012).

In a study conducted in 2015 by Guetterman, Fetter, and Creswell, the authors studied exemplar joint displays by analyzing the various types of joint displays being used in published articles on mixed methods research in health. The authors searched for empirical articles that included joint displays in three journals that publish state-of-the-art mixed methods research. They thus identified and analyzed joint displays

to extract the type of display, mixed methods design, purpose, rationale, qualitative and quantitative data sources, integration approaches, and analytic strategies. The analysis focused on what each display communicated and its representation of mixed methods analysis. Joint displays appear to provide a structure to discuss the integrated analysis and assist both researchers and readers in understanding how mixed methods provide new insights.

We can, thus, suggest that the concept of integration should be used in those studies in which integration occurs from the moment when the original research problem – that is, the question to be solved – is constructed and then extends over the entire research process. The original definition of the research question is the key to establishing that a study has been carried out through the integration of research methods and that integration should extend over the entire process. In other words, precisely specifying the research question is the key thing, and from this, a sense of the best methodological combination will emerge. Researchers must always be ready to adjust the design in light of what is found. Research design is not a stage; it is a process (Fielding and Fielding 2008).

Integration is a multidimensional and complex process, which is built from a social, historical, and cultural perspective. Far from conceiving it as a photograph – that is, a static image – we can compare integration to a film and view it as a construction in motion and permanent change. Indeed, what is interesting about integration is what stems from it.

5 The Role of the Researcher in the Integration of Research Methods

We consider that researchers are social subjects that are culturally conditioned and guided by their personal experiences, which, according to Cipriani (2013, p.53) “are too significant to be completely cancelled.”

At this point, it is worth mentioning the difference between experience and life experience. De Souza Minayo (2010, p. 254), following Husserl (2001), contends that the world of experience is the world of life, the base of all action, as well as all knowledge operation and scientific elaboration. She differentiates the experience from life experience. She says that the latter is constituted as the elaboration of the experiences, and, at the same time, it is related to the historical conditions, making the life experiences an individual experience full of collective sense.

Morse and Field (1995) suggests that the approach chosen by each researcher is his/her own product, given that his/her previous knowledge and the methods he/she will employ define his/her decision when doing research. According to Sandelowski et al. (2009), “data” are not simply “given”; they are constructed by researchers from their perceptions and experiences in interacting with the phenomena studied. Therefore, the approach to be adopted by the researcher affects the research process and its outcomes. The approach is “the fundamental point of view of man and the world that the scientist brings with him or her or adopts in connection with his or her work as a

scientist, whether this point of view has become explicit or remains implicit” (Giorgi 1970, p.126, cited by Ray 2003, p. 149).

May (2006), quoting Benner (1984), points out that it is interesting to consider researchers’ previous experience and notes that expert researchers usually view situations in a holistic manner, based on data drawn from past experiences. May also highlights the importance of pattern recognition, that is, the so-called ability to know where to look, and remarks that the processes of methodologic and disciplinary socialization contribute to such ability. May finally argues that, in addition to his/her extant knowledge – based both on theory and on his/her lived experiences – the expert researcher also relies on intuition and creative reasoning, while she notes that “moving from intuition to insight, from an interesting but quirky question to an important revelation – these processes are not governed by chance” (May 2006, p. 26).

In relation to lived experiences, Hubbard et al. (2001, p. 119) state that “[u]sing our own personal experiences in the field, we present a range of emotional encounters that qualitative researchers may face.” Through an exploration of her own experiences as a researcher of intimate and sensitive topics, Brannen (1988, quoted in Hubbard et al. 2001) argues for the need to protect both the researcher and the subjects of research. The theoretical interpretations made by researchers will also be permeated by those previous experiences. As Morse (2003, p. 7) argues “our perception limits what we consider to be a research problem.”

Sotolongo y Codina and Delgado Diaz (2006, p. 53) point out that persons can only be the result of a process of constitution of subjectivities, and each subjectivity, instead of being centered in itself, is concocted from a context that transcends it and articulates it to others. In these sense, all research process is played in a field of the intersubjectivities “paving the way to interactional and reticular facts as constitutive sources of reality” (Sotolongo and Codina and Delgado Diaz 2006, p. 62).

At this point, it is worth taking into account Cipriani’s assertions (2013, p. 63) quoting Glaser (1978), when he introduces the concept of *theoretical sensitivity*, that is, the ability to gain insight into the subtleties in the meaning of data, distinguishing between what is relevant and what falls outside of the research problem.

For a proper use of integrated research methods, it is necessary for the researcher to first consider quantitative and qualitative methods in a way that does not result in contradictions, as both methods should collaborate with and complement each other in pursuit of a common aim (Bryman 2016). This is only possible where the researcher adopts an open and creative stance and avoids extreme positions.

6 Innovation and the Use of New Technologies for Integrated Methods in Research

Fielding (2012, p. 134) identifies a new approach to methodological integration and points out that “data integration is always a matter of innovation.”

Innovation can be defined as the contribution of something new to scientific knowledge. Innovation cannot be conceived as an individual process as the new combinations of knowledge are based on the interaction and communication of those

that possess such knowledge. The contribution that innovation produces must necessarily be examined within its development context (Dogan and Pahre 1993). Dogan and Pahre also identify different types of innovations, including the so-called methodological innovation as well as theoretical and conceptual innovation (see chapters in the ► [Chap. 61, “Innovative Research Methods in Health Social Sciences: An Introduction”](#) section). The European Commission’s Green Book (1995, p. 4) refers to innovation as being synonymous with the successful production, assimilation, and exploitation of novelty that offers new solutions to problems and allows meeting the needs of both individuals and society. Drawing upon these definitions, we argue that the integration of methods in research can be considered a true process of innovation.

Fielding (2012) explains three innovative forms of data integration that rely on computational support: the integration of geo-referencing technologies and methodologies, the integration of multistream visual data, and the integration of qualitative and quantitative data. The convergence of geographical and social science enables data integration to link outcome-based spatially defined inequalities with process-based investigations of their origins (Fielding 2012). Being able to code, annotate, and analytically manipulate visual representations of physical space helps researchers integrate visual images, words, and numbers not just for context but for analytic reasons (Kwan 2002).

In considering the integration of multistream visual data, Fielding (2012) argues that there is a growing social science interest in visual data, and emergent technologies offer significant enhancements to visual resources. A current innovation involves the increasing range of technologies that capture visual data so that recordings of meetings or fieldwork activities at locations remote from the researcher can be integrated with textual and statistical data.

Finally, the integration of qualitative and quantitative data is perhaps the most popular form, as it involves the use of software such as NVivo, which enables the integration of interviews and observation data with rating scales or survey responses (Fielding 2012).

According to Bazeley (2006), integration has greatly benefited from technology, in particular, computer software (see ► [Chap. 52, “Using Qualitative Data Analysis Software \(QDAS\) to Assist Data Analyses”](#)). However, this is an emerging process that has developed only in recent times, and, while it has gained prominence in the field of research in social sciences, it still has a long way to go until it is finally accepted by the scientific community.

7 Recommendations for Research Projects Utilizing Integrated Methods

Having pointed out the advantages and challenges of using integrated methods, we now present some recommendations that may prove useful when employing these methods:

- (a) As the integration of methods requires knowledge and management of qualitative and quantitative methods, researchers aiming at doing research with

integrated methods are advised to be well-trained in each of these methods or to organize a research team that has expertise in using them. The use of integrated research methods is not advised for novice researchers that have no previous experience in the use of these methods. As argued by Bazeley (2006, p. 65):

Integration of data analysis requires a breadth of skills that has not been commonly available in a single researcher, or alternatively a close-knit multi-skilled team; it requires the capacity to imagine and envision what might be possible – to tread new paths – along with the logic (and skills) required to bring that about.

- (b) Before attempting an integrated methods study, researchers should accurately identify their theoretical, philosophical, methodological, and technical position, so as not to impose their point of view and lose theoretical sensitivity. According to Bergman (2008, p. 28), the separation between qualitative and quantitative methods is related to “delineating and preserving identities and ideologies rather than to describe possibilities and limits of a rather heterogeneous group of data collection and analysis techniques.”
- (c) The increasing use of methodological proposals based on integrated research methods is a major advance in the field of research methodology. However, care should be taken that this is not just a passing fad – which could in the future be replaced by another fad – but that it can truly represent a methodological advance.

8 Conclusion and Future Directions

More than five decades ago, Wright Mills (1961) argued that there are three kinds of interludes in a scientific community: on problems, methods, and theory. In reflecting on the methods, we have discussed in this chapter the origin and characteristics of research processes utilizing integrated methods. First, we agree with Fielding (2012, p. 134) when he argues that “methods have moved from being solely a resource to also being a topic in their own right. Such an approach has a dynamic and demanding view of what makes for an adequate understanding of social phenomena.”

In addition, if we analyze the process of integration of methods in research, we find that the mere inclusion of quantitative data in a qualitative study or the inclusion of qualitative data in a quantitative study does not make the research an integrated methods study. For this to happen, the concept of integration needs to be present from the moment the initial research question is constructed and extend over the entire research process (Tonon 2015).

In this respect, it is worth noting that combining or interacting is not the same as integrating, as integration requires the researcher to adopt a holistic view of the use of methods. According to Moran-Ellis et al. (2006, p. 10) “integration is a particular type of relationship among methods, data, analytic methods, or theoretical perspectives which carries significant implications for how that part of the research process functions.” The issue of theory and ideology deserves separate discussion, and in this sense, it is worth bearing in mind, as Maxwell (2010, p. 477) points out, that

researchers' ontological and epistemological assumptions influence research designs, research questions, conceptual frameworks, methods, and validity concerns.

In this chapter, we also view the integration of methods in research as an innovative process, as "the originality of innovation lies in the process that allows a specific change to take place" (Rodríguez Herrera and Alvarado Uriarte 2008, p. 23). This is an important point to consider for researchers in the twenty-first century because innovation entails the creation of something new which is unknown until that moment.

Dogan and Pahre (1993) point out that innovation is the contribution of something new, but this contribution has to be examined within its development context. At the same time, it is important to consider that the recognition of the value of using integrated methods in research needs to be accompanied by a recognition of the pragmatic and epistemological implications (Moran-Ellis et al. 2006).

Innovative forms of data integration that rely on computational support as the integration of geo-referencing technologies and the integration of multistream visual data are new types of methodological strategies. Today, but much more in the future, the use of software will constitute a common practice, so it is necessary for researchers, particularly the younger ones, to learn how to use it.

Finally it is important to say that the integration of methods in social sciences and health research is a view in the horizon. The possibility of taking this challenge is not only an opportunity but a necessity as well.

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The Use of Mixed Methods in Research

40

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Contents

1	Introduction	696
2	Historical and Philosophical Roots	697
3	Designing Mixed Methods Research Questions	697
4	Mixed Methods Study Designs	699
4.1	Sequential Explanatory Design	699
4.2	Sequential Exploratory Design	700
4.3	Concurrent Triangulation Design (Convergent Parallel Design)	701
4.4	Embedded Design	702
4.5	Transformative Design (Sequential or Concurrent)	703
4.6	Multiphase Design (Sequential or Concurrent)	704
5	Choosing a Mixed Methods Study Design and Getting Started with Your Research	704
5.1	Procedural Diagrams	704
5.2	Study Design Description	705
5.3	Mixed Methods Data Collection and Sampling	705

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5.4	Mixed Methods Data Analysis and Integration	707
5.5	Reporting of Mixed Methods Data	708
6	Challenges in Using Mixed Methods	709
7	Handling Conflicting Results from Mixed Method Studies	710
8	Conclusion and Future Directions	711
	References	711

Abstract

Mixed methods research is becoming increasingly popular and is widely acknowledged as a means of achieving a more complex understanding of research problems. Combining both the in-depth, contextual views of qualitative research with the broader generalizations of larger population quantitative approaches, mixed methods research can be used to produce a rigorous and credible source of data. Using this methodology, the same core issue is investigated through the collection, analysis, and interpretation of both types of data within one study or a series of studies. Multiple designs are possible and can be guided by philosophical assumptions. Both qualitative and quantitative data can be collected simultaneously or sequentially (in any order) through a multiphase project. Integration of the two data sources then occurs with consideration is given to the weighting of both sources; these can either be equal or one can be prioritized over the other. Designed as a guide for novice mixed methods researchers, this chapter gives an overview of the historical and philosophical roots of mixed methods research. We also provide a practical overview of its application in health research as well as pragmatic considerations for those wishing to undertake mixed methods research.

Keywords

Mixed methods · Concurrent triangulation · Sequential exploratory · Sequential explanatory · Convergent parallel · Embedded design · Transformative design · Multiphase design

1 Introduction

Mixed methods research involves the systematic integration of quantitative and qualitative data within a single study, project, or program. This is based on the principle that integration provides a more complete and synergistic utilization of data, versus discrete quantitative and qualitative data collection and analysis. Mixed methods research methodology has advanced significantly in recent years (Creswell and Plano Clark 2018), with its application now bridging a broad range of research questions. Key characteristics of a mixed methods study include the collection and analysis of both quantitative and qualitative data, rigorous methods to collect and analyze the data, use of techniques to execute both data components (either concurrently or sequentially) among either the same participant sample or different samples, and integration of both types of data during data collection, analysis, or discussion. Mixed methods research has several advantages which are discussed throughout the following chapter, but most

importantly, mixed methods provide a more complete picture than either qualitative or quantitative data could provide alone.

2 Historical and Philosophical Roots

In 1962, Thomas Kuhn introduced the concept of a paradigm, which has been described as “an agreed upon theory, worldview, or methodology embodied in the beliefs, practices, and products of a group of scientists” (Johnson and Gray 2010, p. 85). Mixed methods research has been recognized as the third methodological paradigm (in addition to the positivist quantitative and constructivist qualitative dichotomy) with applicability to health and social science research (Doyle et al. 2009). Tashakkori and Creswell (2007, p. 4) define mixed methods as “research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry.” The mixed methods approach combines distinct ideas and practices that distinguishes the approach from quantitative and qualitative paradigms (Denscombe 2008).

While debate exists around the timeframe in which mixed methods research emerged, the origins of mixed methods research can be traced back to the early twentieth century. Research between the 1950s and mid-1970s was primarily quantitative and dominated by the positivist paradigm, in which reality is believed to be measured and observed objectively (Denscombe 2008; Tariq and Woodman 2013). From the mid-1970s to 1990s, the constructivist paradigm, which is associated with qualitative research and the belief that there can be multiple realities and interpretations of the world (Appleton and King 2002), started to emerge as an alternative approach to research. The “paradigm wars” (Bryman 2008; Johnson and Gray 2010) is often recognized as the catalyst for the development of mixed methods research which began to emerge as a distinct paradigm from the 1990s onwards (Denscombe 2008).

Mixed methods have potential to combine the strengths of both quantitative (deductive) research and qualitative (inductive) research, while offsetting some of the weaknesses associated with each individual approach. Pragmatism is considered the “philosophical partner for the mixed methods approach” (Denscombe 2008, p. 273) as it provides a practical method of inquiry and set of assumptions that underpins the mixed methods approach (Johnson and Onwuegbuzie 2004). Pragmatism is outcome-oriented and requires researchers to engage in an iterative process, as they are forced to evaluate their beliefs and approaches in relation to the success and applicability of their practical application.

3 Designing Mixed Methods Research Questions

Plano Clark and Badiee (2010) identify three key elements central to the success of a research study or program – the content area, the purpose of the study, and the research questions. On the surface, developing a research study or program incorporating these three elements seems straightforward. However, the developmental process can be challenging as there are many different approaches for a researcher to

consider. The first step in conceptualizing a mixed methods research study is to start with the big picture by identifying the overall content area. As a researcher, you might be interested in cancer screening, migrant health, dementia, or physical activity. While these topics are quite general, in this first step, it is acceptable to identify a broad, overarching topic as you will start to narrow down your research focus when developing your purpose statement and research questions.

As with any other research methodology, the researcher must have a strong understanding of their chosen topic early on, including the current research evidence and the key research problems. To ensure this, as with any other research study, it is important to conduct a robust review of relevant literature in the chosen topic area (for information on conducting database searching and collating research evidence see ► [Chaps. 45, “Meta-synthesis of Qualitative Research,”](#) and ► [46, “Conducting a Systematic Review: A Practical Guide”](#)). To make a unique contribution to this content area, it is imperative that the research contributes new knowledge to the chosen area; fills a gap in current literature, policy, or practice; and/or identifies an underrepresented population group or issue (Plano Clark and Badiie 2010). It is, therefore, important to conduct your literature review early on, as this will inform development of the purpose statement and research questions.

Once the researcher has developed a strong understanding of the content area and any current deficiencies or opportunities for knowledge advancement in this area, it is time to start narrowing the focus by articulating the purpose of the research. The purpose outlines the study objectives and the primary intent of the research (Plano Clark and Badiie 2010) and sets the direction for the project. Some scholars argue that the need to use mixed methods should be determined by the purpose of the research. That is, if the purpose of the research indicates a need for both quantitative and qualitative approaches, the researcher must then select the most appropriate mixed methods approach (Teddlie and Tashakkori 2009).

Others suggest that it is the research questions, which are more defined and extend from the research purpose, that should dictate the choice in methodology (Johnson and Onwuegbuzie 2004). Bryman (2007), for example, notes that research questions play a pivotal role in the early stages of research, as decisions about the research design and methodology should be made to effectively answer research questions. This is particularly important in mixed methods research, where well-defined research questions guide and keep a study contained by helping to set boundaries and clear directions (Teddlie and Tashakkori 2009). Those who take a pragmatic viewpoint tend to abide by the so-called dictatorship of the research question (Tashakkori and Teddlie 2003, p. 65), considering the research question to be more important than the research method or the underlying paradigm (Tashakkori and Teddlie 2003). Newman et al. (2003), however, propose that researchers follow an iterative, systematic process by considering both the research purpose and research questions when deciding upon an appropriate methodological approach. This approach may also encourage researchers to further refine the focus of their study by developing deeper, more substantial research questions and a “greater awareness of potential multiple purposes” (p. 186).

Regardless of the approach a researcher takes, mixed methods research has been identified as an approach that has great potential to effectively combine insights from

both quantitative and qualitative research into a workable solution, “offering the best opportunities for answering important research questions” (Johnson and Onwuegbuzie 2004, p. 16). Creswell and Plano Clark (2018) add that mixed methods research can help answer complex research questions that cannot be answered using quantitative or qualitative methods alone. This is particularly important in complex fields such as health and social science. For example, earlier we mentioned migrant health as a potential content area of interest. If we decided that the purpose of our study was to understand whether migrants in Western Sydney, Australia, are accessing health services, we could consider asking questions such as: *How frequently do migrants access health services in Western Sydney? Are migrant adults less likely than Australian-born adults to access health services?* We could answer these questions using a quantitative approach, by analyzing data on the number of migrants who access health services. From these data, we might be able to determine whether there are particular migrant groups who are more or less likely to access services, how many migrants are accessing these services, or whether services are more commonly accessed in specific areas, but this approach cannot tell us *why* this is the case. If we were interested in exploring migrant adults’ perceptions of the Australian health system, the services they use regularly and the reasons for engagement, or the barriers they face in accessing health services, we would need to formulate qualitative research questions and use qualitative methods. Both of these approaches can offer important insights that relate to the overarching purpose of the study. The study’s purpose then guides considerations for selecting the most appropriate mixed methods study.

4 Mixed Methods Study Designs

Each mixed methods study design can have different variations, purposes, philosophical assumptions, specific considerations, and strengths and weaknesses (Creswell and Plano Clark 2018). Traditionally, mixed methods study designs have been categorized into two main areas: sequential and concurrent (Castro et al. 2010). Sequential designs are characterized by either the qualitative or quantitative data collection being conducted first, which is then sequentially followed by a second (or further) stage of data collection of the other data type. Concurrent designs, on the other hand, involve the collection of both types of data simultaneously. These data collection approaches have contributed to the development of four major design categories: convergent, explanatory, exploratory, and embedded (Creswell and Plano Clark 2018).

4.1 Sequential Explanatory Design

Sequential *explanatory* design studies have a two-phase design, where quantitative data collection precedes qualitative data collection. The secondary qualitative data collection phase is used to either explain or further explore the quantitative findings

in more depth, as well as aid with the interpretation of the quantitative results (Center for Innovation in Teaching in Research 2017). Sequential explanatory studies can be particularly useful when trying to explain relationships in quantitative data and provide more detail on the mechanisms of those relationships, particularly for surprising or unexpected results (Creswell and Plano Clark 2018). Other strengths of the explanatory sequential design include its straightforward nature (conceptually easy to design, logistically simple to implement, and ease of reporting), its emergent approach (the design of the qualitative phase can be based on the findings from the quantitative phase), its appeal to quantitative researchers as findings can be explored in more depth, and that it can be conducted by a sole investigator (Creswell and Plano Clark 2018). Weaknesses of the sequential explanatory design include challenges in gaining ethics approval for the entire project at the beginning (as researchers may not know how the participant selection for the second phase will be conducted until the first phase has been completed), subjectivity in deciding which quantitative findings require further explanation and who to sample, and that it can be time consuming (due to the two phases of data collection) (Ivankova et al. 2006).

Despite being time consuming, sequential explanatory designs are a commonly used design for randomized controlled trial (RCT) feasibility studies, amongst other applications. The EASE Back study – Evaluating Acupuncture and Standard care for pregnant women with BACK pain – utilized a sequential explanatory approach to inform feasibility of a large randomized controlled trial (RCT) (Foster et al. 2016). Quantitative data on acupuncture and standard care among pregnant women with low back pain was first collected via a survey. This data then informed collection of focus group and interview data, which explored the perceptions of midwives and pregnant women on acceptability and feasibility of acupuncture for the treatment of low back pain during pregnancy. Together both types of data provided a robust rationale for the proposed RCT as well as information on feasibility, recruitment, and consent procedures for the trial. A pilot study of a pedometer-based walking intervention for older adults delivered via primary care in the UK (Mutrie et al. 2012) reported a significant increase in objectively measured physical activity. Focus groups with participants and primary care staff following the intervention identified key elements of the intervention essential to its success but also highlighted the issues of moving such an intervention into routine practice. Nurse-led one-to-one physical activity consultations were highlighted by all focus group participants as being essential to the intervention's success, whereas the use of pedometers was important for some but not all. Walking groups initiated as part of the intervention were poorly attended but were reported as a vital motivator for the small number of regular attendees. Thus, use of a sequential explanatory approach here allowed the specific active ingredients of the intervention to be teased out (Mutrie et al. 2012).

4.2 Sequential Exploratory Design

Studies with a sequential *exploratory* design are very similar to explanatory study designs except that qualitative data are collected first, and this is then followed by a

phase of quantitative data collection. Sequential exploratory designs are most frequently used to identify variables for further exploration (hence the exploratory design), development of an instrument (e.g., a survey), or a classification or theory for testing (Center for Innovation in Teaching in Research 2017). The purpose of the sequential exploratory design is to facilitate the generalizability of results from a small qualitative phase to a larger sample. The strengths of the sequential exploratory design are similar to sequential explanatory design, for example, appeal to quantitative researchers (as qualitative results can be substantiated in the second phase) and that it is also straightforward to implement. An additional strength is that a new instrument, such as a survey, can be produced based on the results of the research process (Creswell and Plano Clark 2018). Weaknesses of the sequential exploratory design are also similar to that of the explanatory design, that is, ethics approval can be sometimes difficult to obtain, the approach can be time-consuming, and the selection of data for exploration in the second phase can be highly subjective. Furthermore, any instruments developed should be valid and reliable, thus additional validation studies are often required (Center for Innovation in Teaching in Research 2017).

As with sequential explanatory designs, sequential exploratory designs are also frequently used in health research, with a common application being the use of qualitative data to inform development of a survey instrument. Keeney et al. (2010) used this approach to examine knowledge, attitudes, and behaviors around cancer prevention among middle-aged individuals in Northern Ireland. This study conducted an in-depth qualitative investigation (through focus groups) on the attitudes and beliefs around cancer prevention behaviors before using the information collected to inform the development of a large-scale cross-sectional survey that ascertained generic beliefs to cancer prevention. Use of this research design facilitated collection of not only in-depth contextual information but also the development of a content valid survey, and thus collection of robust population-based data.

4.3 Concurrent Triangulation Design (Convergent Parallel Design)

The concurrent triangulation design (also known as convergent parallel design) (Castro et al. 2010) is a popular design type, which involves the implementation of both the quantitative and qualitative phases of the research at the same time. Studies with a concurrent triangulation design prioritize both quantitative and qualitative methods equally; however, results are separated for analyses, but then integrated, or triangulated, during interpretation (Tashakkori and Creswell 2007). The main purpose of the concurrent design is “to obtain different but complementary data on the same topic” (Morse 1991a, p. 122) and to bring together the strengths as well as dilute the weaknesses of separate quantitative and qualitative research approaches. Strengths of the concurrent triangulation design include its efficiency of time (both quantitative and qualitative data are collected simultaneously), data analysis can be conducted independently (unlike sequential designs), and that it is intuitive (Creswell and Plano Clark 2018). Despite its popularity, the concurrent

triangulation design also has a number of weaknesses and can be challenging to work with. For example, methodological and interpretation complexities emerge when combining datasets due to differing data, samples, sample sizes, and possibility conflicting data (Tashakkori and Creswell 2007). Logistically, concurrent triangulation studies can be challenging in scope for a research team given the concurrent nature of quantitative and qualitative data collection. A concurrent nested design is similar to the concurrent triangulation design, only instead of weighting both quantitative and qualitative data sources equally, one is given more weight than the other (Castro et al. 2010).

Wellard et al. (2013) used a concurrent triangulation design to identify operational and staffing factors which may influence care quality for individuals living in residential aged care in Victoria, Australia. Cross-sectional survey data on diabetes knowledge of residential staff was collected during the same data collection period as qualitative data was collected via focus groups with a subsample of staff who had also completed the survey. A clinical audit of a subset of case files of residents in the aged care facilities were also examined for diabetes care approaches and incidents related to diabetes. Use of this methodology provided a mechanism that corroborated findings from what was a relatively limited sample size, as well as provides an insight into a range of issues around diabetes care in this setting.

4.4 Embedded Design

The embedded design involves embedding quantitative and qualitative data collection and analysis within a traditional research design (that can be either quantitative or qualitative). For example, researchers conducting an RCT wanting to examine participants' experiences during the trial (e.g., recruitment and retention processes to explore enrolment, compliance, and attrition) could conduct a qualitative exit interview to gather this information. It is important to note that the qualitative study (exit interview) is embedded within the primary quantitative study (RCT) and is not related to answering its aims (i.e., whether the treatment has efficacy), distinguishing the embedded design from the convergent design. Strengths of embedded designs include improvements to (and richer data from) the primary study, being able to incorporate the secondary phase of data collection with relatively little time and resources, and additional research outputs from a single study that may be publishable in higher impact journals (Tashakkori and Creswell 2007). Embedded designs have several limitations including adding complexity and participant burden to the design of the primary study, additional expertise required to analyze the secondary data type (e.g., clinical trialists may need to upskill in qualitative research design, collection, and analysis), and the potential for treatment bias (this can be mitigated by collecting the additional data after the primary endpoint assessment has been completed).

Hoddinott et al. (2009) embedded a qualitative data collection element into their embedded mixed methods cluster RCT, which investigated clinical effectiveness and maternal satisfaction with provision of extra breastfeeding groups for breastfeeding women in Scotland. The primary outcome was the number of babies being breastfed

at 5–7 days, 6–8 weeks, and at 8–9 months (ascertained via routinely collected national databases). Qualitative case study data on operational factors that may affect delivery of the extra breastfeeding groups were collected from a small proportion of primary care staff. These data suggested that limited staff resources, organizational change, and style of management and leadership all affected implementation of the cluster RCT. Addition of these qualitative data partly explained why there was no increase in breastfeeding rates in this area of Scotland despite a small increase in the breastfeeding groups.

4.5 Transformative Design (Sequential or Concurrent)

Studies with a transformative design have two phases and can either be sequential or concurrent (Center for Innovation in Teaching in Research 2017). However, the nature and order of data collection is theory-driven, and integration of results occurs during the interpretation phase (Center for Innovation in Teaching in Research 2017). The transformative lens is used to advance the needs of marginalized or underrepresented populations through a theoretical framework (e.g., feminist theory, disability theory, racial theory, sexual orientation theory) (Mertens 2012). In transformative designs, mixed methods are utilized for ideological purposes, rather than for logistical or methodological reasons (Creswell and Plano Clark 2018). Strengths of transformative designs include the action-oriented nature of the research, empowering communities to action change, and the participatory nature of the involvement of participants in the research (Tashakkori and Creswell 2007). There are several weaknesses associated with transformative designs. Relationships need to be built with participants to establish trust, additional justification is required for using transformative methods, and there is not much structure and guidance on the best way to utilize transformative approaches (Tashakkori and Creswell 2007).

Overarching theories and frameworks can also guide mixed methods studies, such as a quasi-experimental study that utilized mixed methods to explore the effectiveness of a walking program in a disadvantaged area of Brazil (Baba et al. 2017). A sequential transformative approach was undertaken by Baba et al. with the Reach, Effectiveness, Adoption, Implementation, and Maintenance [RE-AIM] framework for evaluating health interventions guiding each phase of their research. The intervention consisted of practical physical activity sessions plus education on behavior change strategies. Quantitative data were used to measure the reach of the intervention to the target group (% of people at the first day of the program/those that were potentially aware of the program through the recruitment strategies), the efficacy of the intervention on increasing physical activity (using a subjective physical activity questionnaire and accelerometers as an objective measure), as well as adoption of the intervention by health professionals at health centers (using quantitative questionnaires). The program was found to increase physical activity over 6 months using the quantitative measures. Despite this, the intervention was not sustained by the health centers, due to workload burden, low attendance, and limited infrastructure and human resources, as identified in the qualitative component.

Without the quantitative component, it may have been assumed the program lacked efficacy. Without the qualitative component, it may have been concluded that the program could be effectively translated into practice over the long term without issues in maintenance (Baba et al. 2017).

4.6 Multiphase Design (Sequential or Concurrent)

Projects with a multiphase design involve an iterative sequence of connected quantitative and qualitative studies that can be either sequential or concurrent. Each study builds on the previous, and together they aim to answer an overarching research question. Multiphase designs are particularly useful in large projects. There are a number of strengths associated with the multiphase design including the provision of a large framework that allows the advancement of an entire program of research, the flexibility of multiple elements of mixed methods research design, applicability in the areas of program evaluation and development, and multiple research outputs (Creswell and Plano Clark 2018). Multiphase designs are also challenging to implement and have several limitations including adequate time and resources (e.g., multiple ethics applications) are required given the scope of projects, problems need to be anticipated early to ensure the adequate adjustment of subsequent studies and the integration and connection of the overall package of the research, and the translation of findings needs to be a continuing focus of the project (Tashakkori and Creswell 2007).

5 Choosing a Mixed Methods Study Design and Getting Started with Your Research

Selection of study design will be partly dependent on the time available for data collection. For example, concurrent approaches are the least time consuming as both types of data are collected at the same time but require more resources at a single time point. Consideration should be given to what is the most practical way of beginning the study, your own research skills (whether you are stronger qualitatively or quantitatively), resources available, and the questions that are being asked.

5.1 Procedural Diagrams

Once the study design has been decided on, the next step in any mixed methods study is to draw a procedural diagram which should include information on data collection, data analysis, and data interpretation. This type of diagram can be very useful in visualizing all the components of a mixed methods research study, can assist with planning of a project, and can easily be constructed in PowerPoint or Word. When drawing a diagram, using notation that will be recognized by other mixed methods researchers (particularly if you are planning to publish your work) is

important. One of the more commonly used notation systems is the one developed by Morse in 1991 where use of capitalization indicates the prioritization given to each form of data (Morse 1991b). The symbols “+” and “→” also indicate sequence, with “+” meaning concurrent and “→” indicating sequential data collection. So, for example, if you were prioritizing quantitative data over qualitative data but collecting the data concurrently, the notation would be:

QUAN + qual

If on the other hand, you were planning to give equal weight to both, but collect quantitative data first, your notation would be:

QUAN → QUAL

Other key elements to include in a procedural diagram are boxes to indicate data collection and analysis for both types of data, circles for interpretation phases of the study, arrows to indicate study sequence, and products and procedures listed as bullet points alongside the boxes (Ivankova et al. 2006). If you were planning a convergent parallel study (Creswell and Plano Clark 2018), for example, with equal weight for each type of data and interpretation at the discussion stage, the diagram would be:

Note that in addition to this basic procedural diagram design, it can also be useful to add in the procedures and/or products of the research at each stage (Creswell and Plano Clark 2018).

5.2 Study Design Description

At the planning stage, it is also useful to write a succinct paragraph describing the study design, including identification of the design (and variant design if applicable), explanation of distinctive features of the design including weight given to each data type, timing of data collection and integration plans, and a rationale for study design selection. This paragraph should be included at the start of the methods section of a paper. It is important not only for self-clarification on appropriate study design selection but is also useful for potential reviewers given many are still unfamiliar with mixed methods research designs.

5.3 Mixed Methods Data Collection and Sampling

Once these initial steps have been carried out, the next stage is to start data collection based on the sequence defined in the study design, either concurrent or sequential data collection. Qualitative and quantitative sampling and data collection are fully described elsewhere in this textbook. Quintessentially, mixed methods data collection is informed by these standard data collection and sampling methods. It is

important to be familiar with these methods, though the exact procedures are dependent on the type of mixed methods design chosen.

5.3.1 Concurrent Data Collection and Sampling

Concurrent data collection is used for concurrent triangulation designs as well as embedded designs and entails independent collection of both qualitative and quantitative data. Both types of data may be independently collected from the same participants in the same time period. For example, McBride et al. (2017) investigated the psychosocial effects of annual whole body MRI screening among individuals diagnosed with a cancer predisposition syndrome by independently collecting qualitative interview data and quantitative survey data within the same time period from the same purposively sampled group of participants. Collecting data from the same participants allows for the data to be converged more easily (Creswell and Plano Clark 2018).

Both types of data may be collected from different participants at the same time, though there should be consideration of confounding when comparing data due to the introduction of individual differences (Creswell and Plano Clark 2018). However, collecting from different groups of participants can be useful in comparing viewpoints. This approach is often used to compare clinician and patient perspectives. Harding et al. (2013) recently used this approach to examine the clinician and patient perspectives of a new triage model designed to reduce waiting times for community rehabilitation programs. In that study, qualitative data were collected from both clinicians and patients at the same time as program appointment waiting times. During data collection, either equal or unequal weight can be given to each type of data. Concurrent embedded designs, for example, often give lesser weight to qualitative data collection during clinical trials.

5.3.2 Sequential Data Collection and Sampling

Several guidelines inform the collection of data and sampling for sequential study designs (sequential explanatory, sequential exploratory, or sequential embedded designs) as these data are collected in stages. Data collected sequentially is not independently collected but instead is related, with one type of data informing collection of the other (Teddlie and Yu 2007). Qualitative or quantitative data can be collected first, with either the first or second data collection weighted more heavily (Creswell and Plano Clark 2018). Sampling of the same or different participants for each phase of the study is also dependent on the study design, with the approach used informed by the research question and emphasis on each type of data in the study.

As detailed above, an exploratory design collects qualitative data first, an approach used by Haider et al. (2017) to investigate a patient centered approach to collection of sexual orientation data in an emergency department (ED). Qualitative interview data were first collected via purposive sampling of patients with ED experiences and ED clinical staff. Once analyzed, these data were then used to inform the development of a national quantitative survey, with participants randomly sampled using random digit dialing and address-based sampling techniques. As described earlier, an explanatory design collects quantitative data first, with the

data used to inform qualitative data collection and sampling. Prades et al. (2017) used an explanatory sequential approach to examine mode of radiotherapy delivery among women with breast cancer by first collecting quantitative data on mode of radiotherapy delivery across several radiotherapy centers, before using these data to inform purposive sampling of department heads for qualitative data collection.

As this brief overview of data collection and sampling techniques indicates, there are a number of approaches to data collection and sampling that can be adopted in mixed methods research. Sampling and data collection can be further complicated with the introduction of more advanced variants of mixed method study design. Selecting a sampling and data collection scheme involves complex decision-making not just on sample size but also on how participants will be selected and the circumstances under which selection will happen. Onwuegbuzie and Collins's paper (Onwuegbuzie and Collins 2007) contains a useful and detailed exposition of these considerations.

5.4 Mixed Methods Data Analysis and Integration

Analysis of mixed methods data initially involves individual analysis of both qualitative and quantitative data components (see also ► Chaps. 47, "Content Analysis: Using Critical Realism to Extend Its Utility," ► 48, "Thematic Analysis," ► 49, "Narrative Analysis," and ► 54, "Data Analysis in Quantitative Research"). It is important to have skills in both types of data analysis in mixed methods research. Analysis timing, order, and integration timing are informed by the rationale for the mixed methods study itself, the overall study design, and the data collection order. Generally speaking, as with data collection and sampling, data is analyzed either sequentially or concurrently (Fig. 1). For example, if a study is conducted sequentially, then data are usually analyzed following each phase with this analysis used to

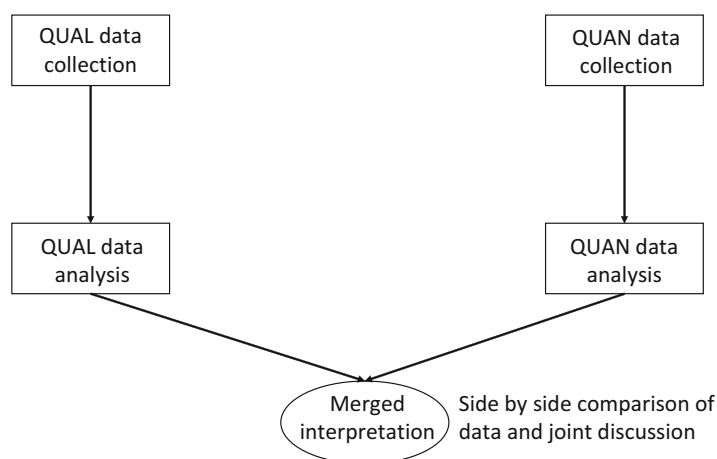


Fig. 1 Procedural diagram convergent parallel study

inform the next data collection and sampling phase. If a study is conducted concurrently, data analysis takes place at the same time with data integration happening immediately following concurrent data collection.

Once the data have been analyzed, they need to be integrated. Integration, when done well, should optimize the strengths of each data collection approach whilst simultaneously minimizing any weaknesses. Effective integration is key to maximizing the mixed methods approach. The concept of data integration can be one of the most challenging concepts in mixed methods research, given that it involves the reconciliation of words and numbers. How data are integrated largely depends on the type of mixed methods research design used. Integration can be done in several ways including merging or consolidation of data, connection of data, and embedding of data (Caracelli and Greene 1993; Creswell and Plano Clark 2018).

1. **Data merging** is where both datasets are jointly reviewed and combined. This form of integration is also sometimes called **data transformation**, which essentially is the conversion of one type of data in to the other so it can be analyzed as one dataset. An example would be transforming qualitative interview data into numeric ratings or converting quantitative data into qualitative narrative (Caracelli and Greene 1993). This integration approach is generally used for concurrent designs as sequential designs are not appropriate for data merging (triangulation), as findings from the first data collection could influence findings from the second data collection, which may result in bias (Onwuegbuzie and Collins 2007).
2. **Connecting the data** is where the analysis of one type of data is used to guide subsequent data collection with no direct comparison of results. This type of integration is used in sequentially designed projects.
3. **Embedding of data** is when more weight is given to one type of data; the other data type is embedded within the first. This approach is commonly used in clinical trials where a small qualitative element is used to supplement data from the trial.

5.5 Reporting of Mixed Methods Data

As well as the commonly expected standards necessary for the write up of any scholarly research, there are additional considerations in the reporting of mixed methods research. First, given that mixed methods research can be complex and often poorly understood, it is usually necessary to define the choice of research design and an emphasis placed on the usefulness of the methodology. Including procedural diagrams (discussed earlier in the chapter) can greatly assist in illustrating research designs. Second, diligent use of subheadings which separate the quantitative and qualitative data collection and analysis can also aid in the understanding of a mixed methods study report. Third, purpose statements for use of each type of data, as well as coherence and cohesiveness of reporting between both data types throughout, will give clarity to the rationale for selecting both data types. Last, any report should be structured in line with each major mixed

methods design, with a well-thought-out structure to facilitate the reader's understanding (Creswell and Plano Clark 2018; see also ► Chaps. 56, "Writing Quantitative Research Studies," and ► 60, "Appraising Mixed Methods Research").

6 Challenges in Using Mixed Methods

Mixed methods studies are challenging to plan and implement, especially when they are used to evaluate complex interventions. The main challenges include (Curry et al. 2013):

1. ***Aligning the research aims with methods and the research team's capacity:*** A rationale for why a mixed methods approach is appropriate and necessary to answer the research question is not always provided in papers. Multi-expertise teams are necessary to conduct mixed methods research, but having such diverse teams can be challenging in handling data as researchers may be biased towards the use of qualitative or quantitative data, particularly if they do not have much mixed methods experience. However, having an interdisciplinary team involved in analysis can be a strength in facilitating rigorous interpretation of the data from several disciplinary viewpoints.
2. ***Following best practice in methodology for each element of the research to ensure rigor throughout:*** Rigor is defined differently for quantitative and qualitative research, and where multi-expertise teams are involved, it can be challenging to ensure that guidelines are strictly followed for the respective study type (e.g., sample size requirements are different).
3. ***Ensuring appropriate integration of qualitative and quantitative elements:*** For integration to be evident, one type of data needs to explain, enhance, confirm, challenge, or quantify the other type of data or one element of the research needs to precede another element, which may lead to subsequent new understanding. Deciding how and when to integrate qualitative and quantitative substudies can also be difficult to decide. This should be driven by the aim and objectives of the study.
4. ***Following guidelines for writing up mixed method work:*** With journal word count limits, it can be challenging to fully report on mixed method research in a single paper. Specific guidance for those writing up mixed method studies has been published, such as Good Reporting of Mixed Methods Studies, GRAMMS (O'Cathain et al. 2008). Quality and rigor of mixed methods research is highly variable in the current literature. Transparency in reporting is essential but often difficult to juggle with word count limits. Reporting guidelines exist to encourage standard reporting and should be followed to assist in the planning phase of studies as well as when writing up completed work (see also ► Chap. 60, "Appraising Mixed Methods Research").

Additional challenges include that mixed methods studies can take longer to conduct than stand-alone qualitative or quantitative studies and often require more funding and

resources. Furthermore, limited methodological guidelines on the conduct of mixed method studies exist. Due to the diversity in such research, researchers have acknowledged that such guidelines would be extremely complex to develop (Zhang 2014). Furthermore, as well as journal word count limits, publication is a challenge in mixed methods research, particularly in the health sciences, where few journals publish this type of study design.

7 Handling Conflicting Results from Mixed Method Studies

The combination of qualitative and quantitative data can lead to different conclusions being drawn instead of a reliance on one type of data alone. Using a framework to assess and explain discordance in results is important for methodological rigor. Moffatt et al. (2006) used such an approach in their RCT which explored the impact of a primary care-based welfare rights intervention on health inequality in older adults from the UK, which collected qualitative and quantitative data concurrently. Impact of the intervention was measured quantitatively using a questionnaire which included subscales on health and wellbeing, lifestyle behaviors, psychosocial interaction, as well as socioeconomic status. Qualitative semistructured interviews on a subset of participants were also conducted to examine perceptions of the intervention, intervention outcomes, and acceptability of the research. Findings from the quantitative data revealed no significant differences in the impact of the intervention between the intervention and control groups. The qualitative data, however, found that the intervention was viewed positively by all those interviewed in the intervention group and that the intervention had important, wide-ranging impacts on those receiving it. To address this discord in findings, the results of that study were further analyzed using this six-step framework:

1. ***Explore the qualitative and quantitative data separately:*** Each element answered distinct, though related, research questions and was therefore expected to return different information.
2. ***Examine the methodological rigor of each subcomponent of the study:*** This included identifying possible reasons why measureable effects may not have been identified in the quantitative dataset. In the qualitative subcomponent, it may have been possible that the subsample differed in some way to the larger sample participating in the intervention study.
3. ***Compare the participants from each subcomponent:*** This revealed no differences between the quantitative and qualitative participants based on social and economic factors or on baseline health and wellbeing data.
4. ***Collect further data to allow more comparisons:*** Longer-term data were collected at 24 months, which supported the initial findings of each substudy.
5. ***Examine if the intervention functioned as planned:*** Unexpectedly, the qualitative interviews identified that prior to the study, many participants were in receipt of welfare benefit for types of services other than the target of this intervention.

6. **Identify if quantitative and qualitative elements match:** The qualitative interviews identified several areas of health and well-being that were not captured by the questionnaires and some areas of mental health were not being interpreted and captured as expected in the quantitative questions. Also, some of the questionnaires were perhaps not as appropriate for this older age target group who reported in the qualitative interviews that they did not expect to see improvements in their physical health at their age (but rather improvements in coping and managing health issues).

Following this framework, the authors were able to conclude that there was a disjunction between the outcomes being assessed quantitatively in the RCT and the outcomes discussed as being important by participants in the qualitative study. This highlights the importance of including mixed methods in evaluations of complex interventions (Moffatt et al. 2006).

8 Conclusion and Future Directions

Integration of quantitative and qualitative data in mixed methods studies has the potential to add rigor and richness to a research inquiry. However, it can be a complex process from the onset given that to date; there is a lack of consensus on methodological approaches. Nonetheless, if the most appropriate and practicable study design is used for the research question, data integration is rigorous and results well reported a deeper and more meaningful understanding of a diverse range of research objectives can be achieved.

Complex and chronic health problems, influenced by aging populations, income disparities, poor lifestyle behaviors, and rising urbanization are becoming increasingly common at a global level. Mixed methods health research will be of growing importance in the future due to the need for an enriched understanding of these health problems. Only by utilizing a pragmatic, mixed methods approach can the complex contributing factors to chronic health conditions be identified, and the active ingredients of interventions be fully understood through comprehensive evaluation.

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The Delphi Technique

41

Jane Chalmers and Mike Armour

Contents

1	Introduction	716
2	What Questions Can Be Answered Using a Delphi Technique?	717
2.1	Forecasting	718
2.2	Reaching Consensus	718
3	Delivery of the Delphi	719
3.1	Anonymity	719
3.2	Postal Delphi	719
3.3	Online Delphi	720
3.4	Other and Combination Approaches	720
4	Using Experts	720
4.1	Defining “Expert”	720
4.2	Size of Panel	721
5	Round One	722
5.1	Provision of Pre-existing Information	723
5.2	Modified Delphi	724
6	Subsequent Rounds	724
6.1	Purpose of Round Two	724
6.2	Developing a Structured Questionnaire for Round Two	725
6.3	Purpose of Rounds Three and Beyond	725
6.4	Providing Feedback	725
7	Delphi Rounds and Reaching Consensus	727
7.1	Determining Number of Rounds	727
7.2	How Much Agreement Is Needed for Consensus?	728
7.3	Stability Indicating Termination	729
8	Reporting Results	729

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715

9	Limitations of the Method	730
9.1	Lack of Standard Guidelines for the Delphi Technique	730
9.2	Sample Size	730
9.3	The Use of "Experts"	731
9.4	Non-responders	731
9.5	Determining When Questioning Should End	732
10	Conclusion and Future Directions	732
	References	732

Abstract

This chapter introduces the Delphi technique and explores its applications relevant to the health field. The Delphi technique is a method of gaining consensus on a particular topic through the use of rounds of questioning of experts in the field. It has three characteristics that make it distinct from other group interaction methods: (1) anonymous group interactions and responses, (2) multiple rounds of questioning, and (3) the provision of feedback to the group between each round. Each characteristic is designed to reduce bias in gaining consensus, such as removing the influence of societal and peer pressures and encouraging the convergence of ideas while still using an anonymous group setting. This chapter will facilitate decision-making in setting up and executing a Delphi study and covers question design, delivery method, employing experts, determining the point of study termination, and reporting of results. Finally, the limitations of the method, particularly the lack of guidelines for researchers, are highlighted to encourage researchers to make a priori decisions which will assist in reducing bias and improving the validity of the Delphi technique.

Keywords

Delphi technique · Consensus · Forecasting · Experts · Stability · Modified Delphi · Panel

1 Introduction

The Delphi technique was originally named after the famous Greek oracle, but despite its name, the technique has no oracular or prophetic powers. Rather, it uses current knowledge and opinions to make predictions about the future or to reach decisions on present questions. Developed by Dalkey and Helmer (1963) for the RAND Corporation, the Delphi technique was originally used to forecast military priorities, particularly with the evolution of technologies. The technique is now much more widely used to make decisions, particularly where hard data to support decision-making cannot be obtained (Linstone and Turoff (1975)). Instead, experts in the relevant field are consulted for their knowledge and experience to make group decisions. It is now commonly used across many areas including computer science, education, psychology, retail, and healthcare, for the purpose of forecasting future events, goal setting, problem-solving, and developing policies.

The Delphi technique generally has three characteristics that make it distinct from other group interaction methods: (1) anonymous group interactions and responses, (2) multiple rounds of questioning, and (3) the provision of feedback to the group between each round (Murry Jr and Hammons 1995). Each characteristic provides the Delphi with a unique approach to gaining consensus on a topic. Anonymous group interactions and responses are thought to better represent the group's true position, as it removes the effect of powerful personalities, individual's status, social pressures of conformity, and peer pressure from group members (Dalkey and Helmer 1963). Multiple rounds of questioning are used on the rationale that "two heads are better than one, or . . . n heads are better than one" (Dalkey 1972, p. 15). That is, input from multiple individuals working as a group is more likely to result in solving a complex issue than from one individual alone. The final characteristic of providing feedback is thought to increase the convergence of ideas within the group to aid in problem-solving. That feedback is given after each round means group members are able to gradually mold their opinion and are more likely to be "swayed by persuasively stated opinions of others" (Dalkey and Helmer 1963, p. 459).

Since the development of the technique, the Delphi has undergone several modifications to allow a wider application. In particular, advancements in technology have enabled the undertaking of online Delphi studies, which greatly improve response times and response rates. The accessibility of literature on the internet has also modified the Delphi. Often, experts are now consulted to provide their input and opinion on a predefined set of variables extracted from the literature, rather than being asked traditional open-ended questions. In healthcare, the Delphi technique is commonly used to determine, predict, and explore group attitudes, needs, and priorities. Many studies consult health professionals as experts in healthcare, but there is a growing body of literature using Delphi studies to problem solve from the health-user perspective, employing patients as experts.

This chapter outlines the key characteristics of the Delphi technique and provides a simple guide on how to employ the technique in a health context. The chapter also provides ongoing examples of how the technique can be used and how decisions about the technique can be made.

2 What Questions Can Be Answered Using a Delphi Technique?

The Delphi technique and its modifications are often used to answer two main types of questions: forecasting and generating consensus. It is important at the outset to understand which category your own research question falls in to. Forecasting is around determining the direction of future trends based on past and present data and soliciting opinions of the expert panel on where a particular area or topic of interest is moving, usually with the aim of directing policy decisions. Generating consensus, most commonly in an area with conflicting evidence or a small evidence base, is used in healthcare to determine practice guidelines, assessment tools, and treatment strategies (Junger et al. 2017), while in research it is often used to design treatment protocols.

2.1 Forecasting

One of the first applications for the Delphi technique since its design at RAND has been forecasting, with initial studies being in the area of defense (Dalkey and Helmer 1963) using experts to determine “from the point of view of a Soviet strategic planner – an optimal U.S. industrial target system, with a corresponding estimation of the number of atomic bombs required to reduce munitions output by a prescribed amount.” When using Delphi to perform forecasting, it is not meant to replace other forms of forecasting, such as statistical models, but rather provide the human input required when current or past data is not comprehensive enough to allow for accurate model forecasting (Rowe and Wright 1999). In a healthcare context, forecasting using the Delphi technique can be used in a wide range of healthcare settings, and forecasting in this context is usually found in the area of policy development, where having an outlook on future directions, trends, and probabilities is crucial to allocating resources to areas where they may be, for example, areas of future unmet need.

Examples of using forecasting to understand future trends in healthcare are diverse and include determining likely rates of illicit drug use and misuse of medical drugs (Lintonen et al. 2014), examining the likely effect of different alcohol control policies (Nelson et al. 2013), and forecasting trends in dentistry techniques and materials needed for tooth restoration (Seemann et al. 2014). The importance of using Delphi to undertake forecasting is that it allows desirable areas or projects (such as successful alcohol reduction initiatives) to be developed; likely but undesirable trends (such as an increase in the misuse of prescription painkillers) can be counteracted, and training for future likely treatments planned.

2.2 Reaching Consensus

Consensus building is one of the primary roles of the Delphi technique in modern-day healthcare research. Consensus guidelines can be very valuable in providing care that is founded on evidence-based “best practice” for a specific clinical problem. By combining the latest healthcare evidence from the scientific literature with expert opinion, this kind of systematic consensus can help form guidelines for areas where the evidence is insufficient or controversial (Boukdedid et al. 2011). For interventions where the complexity of practice can make evidence-based guidelines difficult, such as herbal medicine or psychotherapy, Delphi can provide expert guidance in the creation of practice guidelines and is appropriate where a high-quality evidence base may be lacking (Flower et al. 2007). When using modified Delphi techniques (such as face-to-face discussions at the conclusion of the process) that allow more clarification and discussion, clinically useful tools such as clinical pathway algorithms can be developed more easily (Eubank et al. 2016). In addition to clinical pathways, consensus building via Delphi can provide expert input into the design of clinical trial protocols (Cochrane et al. 2011; Cotchett et al. 2011; Smith et al. 2012) and evaluation of the quality of evidence in clinical trials (Smith et al. 2011). This is

especially useful in the design of trials into complex interventions, interventions where there are multiple likely synergistic components that affect the clinical outcome, due to the unclear nature of which of these may be responsible. However, when developing guidelines or trial protocols, in the absence of strong evidence, caution must be taken as expert opinion on treatment choice may be radically different from how clinicians treat in daily practice (Alraek et al. 2011). It is important to clarify at the outset that one very common misconception with Delphi is that its sole goal is to reach a single consensus, where all members of the panel agree on an issue. This is incorrect; a single consensus should not be the primary goal, and a bimodal distribution of consensus (e.g., where many panelists hold two diverging viewpoints) can be an important finding, especially in areas where there is significant controversy in the literature or evidence base (Linstone and Turoff 2011). Discussion around consensus, and what defines consensus, occurs in more depth in Sect. 7.2.

3 Delivery of the Delphi

3.1 Anonymity

One of the key features of a traditional Delphi is the anonymity of individual responses within the panel (Linstone and Turoff 1975). Anonymity stimulates focus, reflection, and imagination of the individuals (Linstone and Turoff 1975) and removes biases introduced by the effects of status, personalities, and group pressures (Thangaratinam and Redman 2005). The identity of participants should never be revealed, even after the completion of the study; therefore, the method of delivery should be carefully chosen to ensure anonymity is upheld.

3.2 Postal Delphi

Prior to the introduction and wide availability of the internet, Delphi questionnaires were delivered in paper format through post. A postal Delphi is easily administered by the research team and easy to complete by respondents, as well as allowing respondents to fill in the questionnaire at their own pace. However, the administration time of a postal Delphi is much longer than other methods and often incurs low response rates. Salant et al. (1994) recommend a four-step method to improve response rates of a postal Delphi: (1) an advance notice letter; (2) approximately 1 week later, a packet containing a cover letter, the round one questionnaire, and a stamped return envelope; (3) approximately 1 week later, a follow-up reminder notice; and (4) approximately 2 weeks later, a packet containing a new cover letter, a replacement questionnaire, and another stamped envelope sent to those who have not yet responded. With this method, the overall time of administering the postal Delphi will take around 16–20 weeks for four rounds of questioning.

3.3 Online Delphi

The accessibility of the internet has made online Delphi studies much more appealing. An online Delphi allows for faster collection of data, with some studies more than halving the time using an online Delphi versus a postal Delphi (Whyte 1992; Young and Ross 2000). It is also much easier to include a worldwide panel, with turnaround times between subsequent rounds being reduced online and through the post. An online approach also allows for a broader range of data collection methods – online survey, chat room or forum questioning, or even real-time conferencing (Hasson and Keeney 2011; see ► Chaps. 76, “Web-Based Survey Methodology,” ► 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool,” and ► 79, “Asynchronous Email Interviewing Method”).

The availability of free online software has made the online Delphi process much simpler for both researchers and respondents alike. However, there are some factors to take into consideration when using an online process. For example, the security of these freely available software should be taken into consideration. As respondents in a Delphi should remain anonymous, the security of the software is paramount. The availability of a Delphi survey online leaves open the possibility that nonparticipants may access the survey through the URL. One way to avoid this scenario is to provide respondents with a password to be used to access the survey (Young and Jamieson 2001). An online Delphi also limits the inclusion of certain respondents, for example, those people who do not have access to a computer or the internet or those people who are not proficient at using a computer.

3.4 Other and Combination Approaches

In order to improve response rates, many Delphi studies are delivered using multiple platforms of communication. For example, researchers may contact potential panel members via telephone asking for their involvement in the project. The project, however, may be run using a different platform, such as online.

Many Delphi studies are also now delivered using a combined approach; that is, respondents are contacted using various modes and can choose to respond in various modes. This process is thought to improve response times as respondents can choose a method most suitable to them (Okoli and Pawlowski 2004). The most common combined approach is for respondents to be given the option of email, fax, or online submission of their responses (Okoli and Pawlowski 2004). In the interest of time, postal and online methods are rarely combined when delivering a Delphi study.

4 Using Experts

4.1 Defining “Expert”

The Oxford Dictionary defines an expert as “a person who is very knowledgeable about or skilful in a particular area” (<https://en.oxforddictionaries.com/definition/expert>). Unfortunately, broad definitions of experts provide little guidance for

selection of a panel to use within a Delphi study. As such, there is limited consensus as to what standards an expert should meet for inclusion in a Delphi study; however, Mead and Moseley (2001) suggest experts may be defined by their position in a hierarchy, such as those seen within a university structure; by public acknowledgement, such as those who have published widely on a topic; or by their experiences, such as patients who have undergone a certain type of treatment.

Undoubtedly, the core characteristic sought after in an expert is a certain level of knowledge. The difficulty, however, comes with ruling the amount of knowledge necessary for inclusion. When consulting health professionals, knowledge is often benchmarked by level of experience. This is often in the form of a certain qualification or a length time spent working within an area. The danger of these benchmarks is that experience may not always translate to knowledge in the area. That is, to become knowledgeable in a particular area, an individual must go above and beyond simply achieving a certain qualification or undergoing experience: they must have a drive to continue learning within the field. This is of particular relevance in the health sector where advancements in the assessment and treatment of patients are continually evolving, and to maintain knowledge in that area, an expert must actively seek to update their understanding throughout this evolution. When consulting health consumers, knowledge is often benchmarked by the length of time an individual has spent using a service or through their exposure to a certain event, such as surgery. The definition of an expert may vary according to the objectives of a Delphi study. Therefore, it is imperative that researchers develop a set of strictly defined inclusion criteria for potential experts prior to undertaking the study (Mead and Moseley 2001).

When selecting a panel of experts, the homogeneity or heterogeneity of the panel should be considered (Baker et al. 2006). There is merit to both types of panels. A homogenous group of experts may share the same attributes required to reach a consensus, while a heterogeneous group may find it more difficult to reach consensus. The inclusion of a heterogeneous group is thought to increase the validity of findings, because if a varied panel reaches consensus then the findings must be worthwhile (Baker et al. 2006). Of course, obtaining a heterogeneous group may also require a larger panel size which may increase the difficulty of reaching consensus, so is not always advantageous in a Delphi method (Table 1).

4.2 Size of Panel

The number of experts included in a Delphi panel can vary greatly. For example, studies may include as few as 4 participants to as many as 3000 (Thangaratinam and Redman 2005). Linstone (1985) suggests the minimum suitable panel size is seven, which is a generally accepted guide when planning and conducting Delphi studies. However, the final determinant of the size of a Delphi panel is often determined by several pragmatic factors, including, but not limited to, the question to be answered, delivery method, access to experts and resources, timeframe of study, and expenses. A further consideration should be the expectation of a dropout rate between 20% and 30% between subsequent rounds of questioning (Bardecki 1984). Motivating panel

Table 1 Two examples of predefined criteria for determining expert panel member inclusion

Health-user inclusion criteria (Chalmers et al. 2017)	Health professional inclusion criteria (Whitehead 2008)
<i>Aim of study:</i> to determine the areas of life most greatly impacted in women with pelvic pain	<i>Aim of study:</i> to arrive at an expert consensus in relation to health promotion and health education constructs as they apply to nursing practice, education, and policy
<i>Inclusion</i> Female Aged over 18 years Self-reports pelvic pain, defined as pain in the pelvic region and associated structures	<i>Inclusion</i> Senior clinician or academic serving in a nursing area Involved with health promotion policy formation Established public domain research publication record Possess a health promotion-related higher degree qualification

Comment: The health-user inclusion criteria were broad and hence attracted a heterogeneous group for the study. This was in line with the aims of the study. The health professional inclusion criteria were specific and hence attracted a homogeneous group. Again, this was in line with the aims of the study. Notably, the health-user study required three rounds of questioning to reach consensus, while the health professional study with a homogeneous group achieved consensus with only two rounds of questioning

members and ensuring a quick turnaround between rounds of questioning may help to reduce dropout rates (Hsu and Sandford 2007a).

Consensus is likely to be reached in a faster timeframe with smaller panel sizes. However, a small panel size is more likely to represent a homogenous group, limiting the validity of expanding the results beyond that group. A larger panel size will allow for greater heterogeneity among experts, making the results more meaningful to a more varied population. As panel size increases, reliability of findings also improves, and error is reduced (Cochran 1983). However, there are also suggestions that no new ideas are generated nor improvement in results achieved in Delphi studies with panel sizes greater than 25–30 (Delbecq et al. 1975; Brooks 1979). When choosing a panel, the number of experts as well as their quality should be considered.

5 Round One

The initial round of Delphi aims to identify broad statements around each of various areas where consensus is sought. This can be achieved in various ways depending on the specific question(s) that researchers desire to answer. One common technique that is used when the expert opinion (rather than say, previous literature) is paramount is using an open-ended questionnaire. The open-ended questionnaire allows the researchers to solicit information from the panel of experts by providing some open-ended questions. An example of this may be a question such as “List all the components that influence how your patients transition from acute to chronic pain.” In this instance, the researchers are not limiting the information that the experts can provide (Thangaratinam and Redman 2005). This may be more common in areas

where evidence-based practice is limited or where individual opinion guides clinical practice strongly. However, the shortcoming with this open-ended approach is that there may be a wide variety of answers, which may need to be combined or collapsed to allow for the second round to occur, or the researchers risk “survey fatigue” from the large number of items, causing panel attrition and slow response (Custer et al. 1999).

5.1 Provision of Pre-existing Information

In healthcare, especially when designing consensus statements around clinical problems, often researchers wish to use pre-existing research as the basis for round one, then soliciting the panel opinion on the validity or importance of these statements. Figure 1 outlines one way in which this can be done, where a tick-box approach allows a “Yes/No” answer for each of these symptoms. Another similar option would be to have an “Agree/Disagree” option for various statements, as used in this study for developing treatment guidelines for rotator cuff pathology based on a systematic review of the literature (Eubank et al. 2016). In both styles, there is an “other” option, or similar, that allows addition of items that the researchers may not have missed, allowing the panel to feedback their own items. These may then be incorporated into round two, if there is a sufficient common theme that occurs. A final, and very common, way to structure pre-existing information, either from previous literature or the researchers own interest, is to use a Likert, or similar, scale where a numeric rating, usually from 1 to 5, allows the panel member to numerically rate how strongly they agree, or disagree, on a particular statement.

Please select which aspects of your life have been impacted by your pelvic pain:

- ☐ Jogging or running
- ☐ Getting to sleep at night
- ☐ Household activities such as cooking or cleaning
- ☐ Sitting for longer than 20 minutes
- ☐ Riding bicycle
- ☐ Staying asleep during the night
- ☐ Wearing tight fitting clothes

☐ Other (please elaborate):

Fig. 1 An example of round one questioning in a Delphi study identifying significant quality of life impact areas in women with pelvic pain. Here, eight aspects are shown. In the actual study, 52 aspects were identified through the literature and were included in round one. *Comment:* The availability of the “other” section allows for a qualitative addition by respondents if their experience was not reflected in the impact areas provided. This is essential when round one questionnaires have been developed in consultation with the literature to ensure that real-life experiences of the experts can be added to the information published within the literature

An example of this may be around how important it is to explain side effects of a medication to patients, with responders rating from 1, not at all important, to 5, vitally important. There are, therefore, a number of question styles that can be used, depending on the quantity and importance of any pre-existing information.

5.2 Modified Delphi

There are numerous modifications to the Delphi technique, although all of these maintain the same overall intent as the original technique (to predict future events or arrive at consensus) and the same overall procedure (multiple rounds using a panel of selected experts). The original Delphi technique is designed to be used with an open-ended questionnaire, as outlined above. The most common modification is that instead of an open-ended questionnaire, the researchers use a carefully selected set of preselected items (such as in Sect. 5.1 above). Two significant advantages of this modification are an increase in the response rate and a solid foundation in pre-existing knowledge (Custer et al. 1999). Other modifications can include the inclusion of a “face-to-face” discussion at the end of the initial anonymous rounds (Eubank et al. 2016; Schneider et al. 2016). This final “face-to-face” round can serve a number of purposes including allowing easier discussion and presentations of clarification and justification for certain points and allowing easier clarification of disagreements. However, this also means that one of the key principles of Delphi is broken, allowing one or more dominant personalities to overpower others (Boulkedid et al. 2011). Another variant can be that these initial recommendations (developed during the anonymous rounds) can be given to a separate panel of experts, for example, physicians, to comment on, and then their recommendations can be returned to the anonymous panel for further round(s) of consensus. This ensures that the expert recommendations are feasible for clinical practice (van Vliet et al. 2016) and avoid the issue of discrepancy between experts and clinicians (Alraek et al. 2011).

6 Subsequent Rounds

6.1 Purpose of Round Two

The aims of round two are to prioritize or rank items discussed in round one and provide justification for their ranking (Hsu and Sandford 2007a). In this process, a more structured questionnaire is created based on the responses received in the first round, and respondents are asked to quantitatively rate or rank order their responses in order to prioritize them (Ludwig 1994). Respondents can also then use qualitative responses to supplement their ratings, providing justification for their chosen ratings. As a result of round two, areas of agreement and disagreement between respondents begin to emerge, and a level of consensus can be identified (Hsu and Sandford 2007a).

6.2 Developing a Structured Questionnaire for Round Two

On the completion of round one, responses are then used to develop a more structured questionnaire for further rounds of questioning and clarification. As most round one surveys are conducted in a qualitative manner, there are few guidelines on the exact procedure to then develop a structured questionnaire. Research teams should aim to identify themes from the round one qualitative responses, remove duplicates of any responses, consolidate themes and responses, and unify terminology used (Okoli and Pawlowski 2004). Often, there is a need to collapse responses in order to shorten the subsequent round questionnaires (Keeney et al. 2001). An inclusive approach where responses have not been collapsed can result in large questionnaires for subsequent rounds, which may put off panel members participating.

Once key themes have been identified and the overall content of the questionnaire has been finalized, the method of response from the expert panel should be considered. Whether respondents are asked to rank or rate items will influence the type of data gathered and the subsequent data analysis. Rating of items indicates how respondents feel about individual items within the questionnaire, whereas ranking of items asks respondents to compare all items to one another and order according to their preference. Linear numerical scales, such as those described by Likert (1932), are commonly used as a means of collecting rated responses. Care should be taken to select a validated scale to collect quantitative responses (Hasson and Keeney 2011). While closely related, rating and ranking are separate entities, and the choice to use one or the other or both should be considered in conjunction with the aims of the Delphi study (Figs. 2 and 3).

6.3 Purpose of Rounds Three and Beyond

Subsequent rounds of questioning serve to allow respondents to revise their judgments or to provide justification for remaining outside of the consensus (Pfeiffer 1968). In rounds three and beyond, feedback on the group and the individual respondents' position is provided from the previous round structured questionnaire, and respondents can clarify their rationale for differing from the group. Often, there is only a slight increase in the degree of consensus in subsequent rounds of questioning (Dalkey and Rourke 1971; Weaver 1971), and as such, Delphi studies often include only three rounds of questioning. Theoretically, Delphi studies could continue for many number of rounds before reaching the required consensus, although three is often enough to obtain sufficient consensus (Hsu and Sandford 2007a).

6.4 Providing Feedback

The provision of feedback between each round will be dependent on the aims of the study and the format of questions included in the Delphi. Qualitative content

<i>In the past month, how much has your pelvic pain affected your:</i>	Not at all (0)	A little bit (1)	Somewhat (2)	Quite a bit (3)	A great deal (4)
energy levels?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
mood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
sleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
stomach and intestinal function?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ability to sit for longer than 20 minutes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ability to perform and function normally in your everyday role?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ability to take part in physical activity?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ability to wear certain clothes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 2 An example of structured questioning in round two in a Delphi study identifying significant quality of life impact areas in women with pelvic pain. *Comment:* In this example, respondents use a qualitative scale to provide answers. The qualitative aspect of the scale was also piloted on the expert panel members to ensure its ease of use. The scale has also been validated as a numerical Likert scale (see Chalmers et al. 2017), with numbers 0–4 corresponding with the qualitative responses

<i>In the past month, how much has your pelvic pain affected your:</i>	Your last score	Group's last score	Your new score					Comment
			Not at all (0)	A little bit (1)	Somewhat (2)	Quite a bit (3)	A great deal (4)	
energy levels?	4	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
mood?	3	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
sleep?	3	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
stomach and intestinal function?	4	4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ability to sit for longer than 20 minutes?	4	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ability to perform and function normally in your everyday role?	3	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ability to take part in physical activity?	2	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ability to wear certain clothes?	3	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Fig. 3 An example of feedback after round two in a Delphi study identifying significant quality of life impact areas in women with pelvic pain. Feedback delivered to respondent one (Tables 2 and 3). *Comment:* Feedback received should include the respondent's previous rating along with the group's previous rating, for the respondent to consider their position in relation to the group's. Respondents also have the opportunity to provide further comments and are instructed to provide comments on times where ratings have changed or where they do not wish to change their rating but remain an outlier in comparison to the group's median rating

analysis techniques are usually used after the first round to identify key themes from the unstructured questionnaire (see also ► Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility”). These are then used to create the structured questionnaire in subsequent rounds. In rounds three and beyond, feedback can be

numerical or statistical, providing an overview of the group position, with supplemental qualitative data such as rationale responses or other comments. Quantitative feedback generally consists of central tendencies (mean, median, or mode) and level of dispersion (standard deviation or interquartile ranges) (Thangaratinam and Redman 2005; Hsu and Sandford 2007a). Respondents are also given specific feedback on their individual responses from the previous round in relation to the group. This gives respondents the opportunity to revise their responses in light of the group responses (Powell 2003).

7 Delphi Rounds and Reaching Consensus

7.1 Determining Number of Rounds

Delphi studies can continue for any number of rounds, and there have been up to 25 rounds of questioning reported (Couper 1984). However, Delphi studies generally use a maximum of three or four rounds of questioning before termination. The termination of rounds should occur when either consensus is reached, when “there is enough convergence to justify using the results without complete consensus” (Whitman 1990, p. 378), or when stability of responses is achieved (Dajani et al. 1979). With successive rounds of questioning, the variability in results will generally stabilize. This can either indicate a convergence of responses (Murry Jr and Hammons 1995) toward consensus or that the panel members are unmoving in their responses between rounds (Dajani et al. 1979). In these instances, consensus on the topic may never be reached, but the stability of responses should indicate that terminating the survey is appropriate. See Tables 2, 3, and 4 for examples of consensus and stability.

Another consideration for determining the number of rounds in a Delphi study is the dropout rate of expert panel members. Some dropout between rounds of

Table 2 Results of respondents in round two of a Delphi study identifying significant quality of life impact areas in women with pelvic pain

	Impact area							
	Energy	Mood	Sleep	Stomach/ intestinal function	Sitting	Daily functioning	Physical activity	Wearing certain clothes
Respondent	1	4	3	3	4	3	2	3
	2	4	4	2	3	2	3	0
	3	3	3	2	4	2	4	3
	4	1	2	2	2	0	1	0
	5	4	3	4	4	3	2	3
	6	3	3	3	4	3	2	3
	7	1	1	0	2	0	1	0
Median	3	3	2	4	2	3	2	2
IQR	2	0.5	1	1.5	2.5	1	1	3

IQR: interquartile range. Colour code: IQR indicates consensus not reached IQR indicates consensus has been reached

Comment: Overall agreement between respondents in round two was 23.2%. However, inspection of the IQR for each impact area shows that consensus appears to be reached on four out of eight areas. To obtain a higher level of consensus, a third round of questioning was used (Table 3)

Table 3 Results of respondents in round three of a Delphi study identifying significant quality of life impact areas in women with pelvic pain

		Impact area							
		Energy	Mood	Sleep	Stomach/ intestinal function	Sitting	Daily functioning	Physical activity	Wearing certain clothes
Respondent	1	4	3	3	3	4	3	2	1
	2	4	4	2	3	2	3	3	0
	3	3	3	2	4	2	4	4	2
	4	4	3	2	2	2	1	1	0
	5	4	3	4	3	4	3	2	3
	6	3	3	3	4	3	3	2	2
	7	4	3	2	2	2	2	0	0
Median		4	3	2	3	2	3	2	1
IQR		0.5	0	1	1	1.5	0.5	1	2

IQR: interquartile range. Colour code: IQR indicates consensus not reached IQR indicates consensus has been reached

Comment: Overall agreement between respondents in round three was greater than round two, at 34.5%. Although this is seemingly low, inspection of the IQR for each impact area shows that consensus appears to be reached on six out of eight areas

Table 4 Wilcoxon signed-rank test results comparing responses from round two and three of a Delphi study identifying significant quality of life impact areas in women with pelvic pain

	Impact area							
	Energy	Mood	Sleep	Stomach/ intestinal function	Sitting	Daily functioning	Physical activity	Wearing certain clothes
Z-score	-1.414	-1.342	-1.00	-1.414	-1.414	-1.00	0.000	-1.633
Significance	0.157	0.180	0.317	0.157	0.157	0.317	1.000	0.102

questioning is to be expected (Bardecki 1984), and the research team should anticipate this in their consideration of the size of the expert panel. The makeup of the expert panel should be assessed after each round to ensure the uniformity of the panel remains as was intended. Dropouts have the tendency to modify a once heterogeneous group into a more homogenous group, which can influence findings (Wheeller et al. 1990). Where the panel size significantly diminishes or the uniformity of the panel changes, the survey should be terminated.

7.2 How Much Agreement Is Needed for Consensus?

Consensus is essentially the amount of responses that fall within a prescribed range (Miller 2006), and it is imperative that consensus is determined prior to the beginning of the Delphi study. However, there is little guidance from the literature that will help researchers to determine a level of consensus, and different levels may be set depending on the aspirations of the research team, the question being asked, the type of responses given, and the number of expert panel members consulted.

Many Delphi studies define consensus as a certain percentage of respondents being in agreement. The particular level of agreement is often arbitrarily chosen and may range from 100% down to as little as 51% (Williams and Webb 1994;

Heiko 2012). Other studies are even less specific with the set level of agreement, using unclear values (Beech 1997) or terms such as “good enough” (Butterworth and Bishop 1995, p. 30) agreement. A more objective and rigorous method of determining consensus is through the use of interquartile range (IQR). The IQR is the measure of dispersion around the median, consisting of the middle 50% of responses. The range of the IQR is usually dependent on the number of response choices available, with more response choices usually resulting in larger IQRs. There are some basic guidelines that may assist with interpreting consensus using IQRs: where the number of response choices is ten or more, an IQR of two or less can be considered consensus (Sheibe et al. 1975); where the number of response choices is four or five, an IQR of one or less can be considered consensus (Raskin 1994; Rayens and Hahn 2000). Tables 2 and 3 outline an example of determining consensus using level of agreement and IQRs.

7.3 Stability Indicating Termination

Stability of a Delphi study occurs when there is little shift in the distribution of responses from one round to another. Whether responses are stable or instable is determined through statistical means. Where the statistical analysis indicates that responses have not differed between two subsequent rounds, the Delphi survey should be terminated. Similar to level of agreement, there are no set guidelines for how this statistical analysis should be conducted. The choice of statistical method to determine stability will depend on the questions asked in the survey and the type of responses provided. More information on different techniques of determining stability can be found in reviews by von der Gracht (2008, 2012). Some common examples include the Wilcoxon sign-ranked test, Chi-squared test, intra-class correlation coefficient, and Kendall’s W coefficient of concordance. Table 4 provides an example of determining stability levels using a Wilcoxon sign-ranked test.

8 Reporting Results

A common issue with Delphi is that due to the wide variety of modifications, there is often a lack of clear reporting around both the technique itself, including vital information such as the definition of consensus, how the experts were selected, and which, if any, modifications to the original Delphi technique were used (Boulkedid et al. 2011). This lack of clarity in reporting the methods often undermines the conclusions from then Delphi as it is unclear if the process was followed correctly. To assist with standardize reporting of Delphi, there have been attempts to generate guidelines for reporting of Delphi in the past (Hasson et al. 2000), but these have not focused on development a checklist approach similar to other reporting guidelines such as SPIRIT (Chan et al. 2013) which has limited their usefulness. The use of a checklist can improve not only the reporting but, if used at an early stage, the

design of the study as it helps identify decisions that need to be made with design choices early on. The Guidance on Conducting and REporting DELphi Studies (CREDES) guideline provides the first checklist approach for evaluating study quality (Junger et al. 2017). This checklist covers the rationale for using Delphi. Some key areas include the design process including how consensus will be designed and what to do if consensus is not reached, how the initial information is generated (sources and how it was synthesized), how the experts are selected, and a flow chart outlining the number of rounds including the preparation phases. The use of a checklist such as this, or other checklists that are currently in development such as the “Reporting E-Delphi Studies (REDS) in health research checklist,” is strongly encouraged to improve design.

9 Limitations of the Method

This chapter has outlined some of the uses and benefits of employing the Delphi technique; however, there are a number of limitations of this technique that should be highlighted.

9.1 Lack of Standard Guidelines for the Delphi Technique

The mixed qualitative-quantitative design of the Delphi technique does not allow for studies to follow a standardized scientific approach as is possible with other study methodologies. As such, there is wide variation in the ways the Delphi technique has been implemented in the literature. The only general guidelines that exist for the technique are the requirement to provide feedback to respondents between rounds and to include at least two rounds of questioning to reach consensus (Keeney et al. 2010). However, even the method of feedback provided can range from a single number to group distributions or qualitative responses of the respondents. The lack of guidelines for the Delphi technique has resulted in some researchers questioning the validity of the methodology (Sackman 1975), although others view it as beneficial, with the flexibility of the technique allowing researchers to answer a broad range of questions (Keeney et al. 2011). While efforts have been made to create guidelines and recommendations for the Delphi technique, there is still no standardized method for undertaking a Delphi study (Keeney et al. 2001; Hasson and Keeney 2011).

9.2 Sample Size

As discussed in Sect. 4.2, the number of expert panel members in a Delphi study can vary greatly. There are no guidelines for selecting the number of expert panel members with the Delphi technique, and so the decision is often made empirically and pragmatically based on several factors (Thangaratinam and Redman 2005).

The size and type of the expert panel may limit the findings of a Delphi study: a smaller, homogeneous panel may reach consensus quickly but has limitations on the expansion of results to a heterogeneous population; a heterogeneous panel may take longer or indeed fail to reach consensus but allows for results to be validly extrapolated to a broader population. The size and makeup of the panel should be determined with the aims of the study in mind.

9.3 The Use of “Experts”

The definition of an expert suitable for inclusion in a Delphi study is not well defined. Often, the definition of an expert being included is based on the objectives of the study being run. With healthcare professionals, experts may be classified according to their level of qualification, although this has limitations in assuming that a qualification equals experience and expertise. With healthcare users, experts may be classified as patients or groups who have a certain condition or have undergone the same procedure or treatment. That the makeup of a panel can vary greatly highlights the need for a clear set of inclusion criteria prior to the beginning of a Delphi study.

While the Delphi technique is used to reach consensus, there is also an argument that consensus in a Delphi study does not necessarily mean a correct answer has been achieved (Keeney et al. 2011). Unfortunately, the use of statistical analysis methods often means that extreme opinions can be masked (Rudy 1996), and respondents who hold opinions that stray away from the mean are most likely to drop out of Delphi studies (Bardecki 1984). The anonymity of the Delphi technique theoretically allows respondents with minority views to retain their opinion, but some researchers also question the issue of social pressure and conformity despite this anonymity (Keeney et al. 2011).

9.4 Non-responders

As with all study designs with repeated measures, there is a risk of dropouts or non-responders in the Delphi technique. There is no set percentage of attrition that is acceptable in Delphi studies, but a dropout rate of 20–30% can be expected between rounds (Bardecki 1984), and this should be taken into consideration when determining the panel sample size.

Hsu and Sanford (2007b) recommend several strategies for dealing with non-respondents in a Delphi study. First, the use of follow-up reminder strategies should be implemented to nudge nonrespondents into filling in their questionnaires. Second, setting deadlines can help researchers avoid nonrespondents slowing down the Delphi process. If several follow-up reminders have been sent in the days or weeks following a round of questioning, it is reasonable to proceed with the study and classify any nonrespondents at that point dropouts. Finally, the provision of incentives for respondents can help to reduce dropouts. Incentives may be provided

at the submission of each round to encourage participation or given at the conclusion of the final round of questioning as a gesture of thanks.

9.5 Determining When Questioning Should End

Both stability and consensus provide some general outlines for when questioning should end. However, there are no set guidelines on the cutoff level that should be used to determine the end of a Delphi study. Often, this figure is set arbitrarily and decided upon post hoc or omitted entirely from studies (Keeney et al. 2011). The particular level of consensus should be determined prior to a study beginning. Setting the consensus level may depend on several factors, including the questions posed, the expected outcomes, the homogeneity or heterogeneity of the panel, and the size of the panel. In studies where consensus is not reached should not necessarily be viewed negatively. Results not reaching consensus indicate that expert opinion differs among panel members, which can be interesting and clinically meaningful results in themselves.

10 Conclusion and Future Directions

The Delphi technique, when properly designed and reported, can be a powerful tool to answer questions for healthcare researchers around future trends and in decision-making in areas where there is a lack of, or conflicting, evidence. Due to the lack of standard guidelines around the Delphi technique, careful consideration by the researchers must be given to ensure that the criteria for “experts,” the pre-synthesis of any information, and definition of consensus (if required) are clearly thought out a priori and clearly reported in any publications, preferably using one of the emerging guidelines for Delphi reporting such as CREDES. Given the new focus on ensuring healthcare outcomes from clinical trials are able to be translated from the more “ideal” clinical trial context into practice, the use of Delphi, including its modifications of face-to-face meetings, to ensure that trial design both reflects and is able to influence clinical practice, through the use of key stakeholders, is an important consideration moving forward. This has the potential to change the landscape of clinical trial design, especially when considering complex interventions or multidisciplinary teams working on complex, and often chronic, healthcare issues.

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Consensus Methods: Nominal Group Technique

42

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Contents

1	Introduction to Nominal Group Technique (NGT)	738
2	When and Why to Use NGT	738
2.1	Guideline Development	739
2.2	Identifying Research Priorities	739
2.3	Establishing Core Outcomes	740
3	Methods	741
3.1	Participant Selection and Recruitment	741
3.2	The Facilitator	741
3.3	Conducting the Nominal Group Technique	742
3.4	The Modified NGT	743
3.5	Data Analysis	744
4	Advantages and Disadvantages of the NGT	745
4.1	Considerations for Involving Patients in NGT	746
5	Conclusion and Future Directions	747
	References	748

Abstract

Nominal group technique uses structured small group discussion to achieve consensus among participants and has been used for priority setting in healthcare and research. A facilitator asks participants to individually identify and contribute

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ideas to generate a list. The group discusses, elaborates, clarifies, and adds new ideas as appropriate. Each participant independently prioritizes the ideas, for example, by voting, rating, or ranking. The facilitator may summarize the scores to ascertain the overall group priorities. This method is useful for generating a diverse range of views and ideas in a structured manner, prevents participants from dominating the discussion, and promotes input from all members.

Keywords

Nominal group technique · Consensus methods · Focus group · Ranking

1 Introduction to Nominal Group Technique (NGT)

The nominal group technique (NGT) is a structured group process used to achieve consensus among participants. The process involves participants identifying and contributing ideas toward a topic or question specified by the facilitator. Participants then discuss and individually prioritize the ideas. There are variations on how the prioritization can be done, for example, by voting, rating, ranking, or a combination of methods. The facilitator may summarize the individual scores to produce a set of prioritized ideas that represent the group's preferences. Using the NGT as a method of consensus generates a diverse range of views and ideas in a structured manner, ensures that the opinions of all group members are taken into account, and prevents the discussion and process being dominated by an individual participant.

The NGT was developed by Delbecq and Van de Ven in 1968 and has since been applied in a variety of fields, particularly in health and social research (Delbecq et al. 1975). This chapter will discuss when and why to use NGT, present some examples of NGT studies in health, provide an overview of the methods involved in conducting a NGT, outline the advantages and disadvantages of using NGT, and discuss future directions in terms of potential applications and developments in NGT.

2 When and Why to Use NGT

The NGT is used to generate and prioritize ideas and to achieve group consensus on a particular topic. The James Lind Alliance (Cowan and Oliver 2013), an organization that facilitates research priority setting partnerships, suggests that NGT may be useful when:

- There is concern about participants not contributing.
- Some participants are more outspoken than others.
- The group does not easily generate many ideas.
- Some participants think better in silence.
- The topic is contentious or there is serious disagreement.

In health and social research, the NGT has been applied in numerous studies across a broad range of topics and with diverse groups of participants, including patients, caregivers, and health professionals. Some applications of the NGT include research priority setting (Knight et al. 2016; Ghisoni et al. 2017; Lavigne et al. 2017; Williams et al. 2017), eliciting patient priorities and treatment outcomes (Sanderson et al. 2010; Howell et al. 2012; Urquhart-Secord et al. 2016), identifying patient and caregiver challenges and needs related to chronic conditions (Miller et al. 2000; Dewar et al. 2003; Sav et al. 2015), identifying preferences for end-of-life care (Aspinal et al. 2006; Dening et al. 2013), and identifying exemplars of patient-centered professionalism in nursing and pharmacy (Hutchings et al. 2010, 2012). Some detailed examples of NGT studies used in guideline development, research priority setting, and establishing core outcomes will be provided in the following section.

2.1 Guideline Development

The World Health Organization (2014) has recognized the need to use formal consensus methods in the development of clinical practice guidelines and often use the NGT to identify priorities of stakeholders for integration into healthcare recommendations. For example, the NGT may be used to inform guideline development through the generation and prioritization of guideline topics, with participants being asked questions such as, “What are the main issues that need to be addressed by guidelines for this disease/condition/treatment?” The NGT has been successfully used to inform the development of guidelines for dementia (Trickey et al. 1998), intensive care (Rolls and Elliott 2008), and treatment of vulvovaginal candidiasis (Bond and Watson 2003), among others.

Rolls and Elliott (2008) used the NGT in combination with other group processes to develop state-based clinical guidelines for six common intensive care practices – eye care, oral care, endotracheal tube management, suctioning, arterial line management, and central venous catheter management. Clinicians, academics, and staff from the Intensive Care Coordination and Monitoring Unit participated in the guideline development process which included a preparatory educational seminar, formation of working groups, and identification of scope of practice for each guideline. A consensus development conference was conducted, and the NGT was used to develop recommendations for practice.

2.2 Identifying Research Priorities

Research priority setting partnerships are increasingly being conducted to involve stakeholders in a transparent process to prioritize health research, to help ensure that resources are directed toward areas of high priority and address important needs. The James Lind Alliance (JLA) was established in 2004 to facilitate a priority setting partnership among patients, family members, and health professionals to identify

and prioritize unanswered questions about treatment that they agree are important (Cowan and Oliver 2013). The process involves consultation, and the collation and prioritization of research questions (treatment uncertainties). The JLA recommends the NGT to prioritize research topics, and it has been used in a many of their partnership initiatives including in asthma, prostate cancer, urinary incontinence, schizophrenia, and kidney disease.

Rees et al. (2017) conducted a research priority setting exercise in gestational diabetes mellitus using the JLA approach. The steering committee short-listed research priorities obtained through a survey and review of clinical practice guidelines. They used the NGT in the final workshop to identify the top 10 research priorities.

2.3 Establishing Core Outcomes

In clinical trials, treatments are developed and tested by researchers to make sure they are effective and safe. Researchers look at the effects those treatments have on patients by measuring outcomes, which are things that can arise or change because of a health condition or treatment (see ► Chap. 37, “Randomized Controlled Trials”). However, outcomes that are measured in research are often not appropriate or meaningful to end users (i.e., patients) (Yudkin et al. 2011). In addition, there is large heterogeneity in the reporting of outcomes, resulting in the inability to compare the effectiveness across trials, ultimately contributing to research waste (Manera et al. 2017). In view of this, there is growing recognition of the need for core outcomes informed by all stakeholders. Core outcomes are defined as outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or healthcare. Developing a standardized set of core outcomes will improve the consistency in reporting of outcomes that are critically important to patients, caregivers, and their clinicians. A number of global and discipline-specific initiatives develop core outcome sets, including the Outcome Measures in Rheumatology (OMERACT) initiative and the Standardized Outcomes in Nephrology (SONG) initiative. Both initiatives recommend and implement the NGT as a method to reach consensus on core outcomes (Boers et al. 2014; SONG Initiative 2017).

As part of the SONG initiative, an international nominal group technique study was conducted to identify patient and caregiver priorities for outcomes in hemodialysis (Urquhart-Secord et al. 2016). In total, 82 patients on hemodialysis and their families from Australia and Canada were recruited to participate in 12 nominal groups. The study used a combined focus group/nominal group technique to identify and rank outcomes, and to discuss the reasons behind the ranking decisions. Qualitative data analysis of the group discussions was done using thematic analysis to generate themes and subthemes. Quantitative data analysis used the individual rank scores of each participant to determine a mean rank score for the top 10 most important outcomes, based on the number of people who ranked each outcome. Across all groups they identified 68 different outcomes. The top ranked outcomes were fatigue/energy, survival, ability to travel, dialysis-free time, impact on family,

ability to work, sleep, anxiety/stress, decrease in blood pressure, and lack of appetite/taste. Four themes were identified which explained their choice and prioritization of outcomes: living well, ability to control outcomes, tangible and experiential relevance, and severity and intrusiveness.

3 Methods

3.1 Participant Selection and Recruitment

The NGT seeks to generate a range of ideas or solutions to a specified topic; thus key informants (i.e., people with relevant expertise or experience) should be selected to participate. For example, a NGT study aimed at identifying important issues for palliative care patients and their families conducted groups with patients, bereaved relatives, and healthcare professionals with direct experience and interest in palliative care (Aspinal et al. 2006). As it may not be feasible to recruit all eligible participants, a purposive sampling strategy can be applied, whereby participants with a diversity of demographic characteristics are selected to obtain a range of perspectives.

The number of participants per group usually ranges from six to eight, although groups have been run with as few as two and as many as 14 participants (McMillan et al. 2015). However, too few participants may reduce the potential for idea generation and discussion if the group dynamic is lacking, while very large groups may be difficult to manage, and it may not be possible to elicit detailed input from all participants.

3.2 The Facilitator

The facilitator (also known as a moderator) plays a key role in the NGT as their task is to encourage and help participants contribute their ideas while guiding the group through the NGT process. The facilitator therefore acts as the group leader, and it is important for them to be trained in conducting NGT, as an untrained facilitator may influence the quality of the data collected. The facilitator must also have sufficient knowledge of the topic under investigation and must understand the informational goals which are trying to be achieved. These factors are important because the way in which the questions are framed by the facilitator will impact the quality, breadth, and depth of the responses (Elliott and Shewchuk 2002).

In addition to having adequate content knowledge, the facilitator must be able to build rapport and provide a comfortable setting for participants to support and stimulate thoughtful and relevant discussions. This includes being respectful and nonjudgmental of participants' views, being patient and sensitive to their needs, and ensuring the confidentiality of the discussion. If participants are unknown to each other, the facilitator may also prepare an icebreaker exercise to build rapport so that participants can have open, free-flowing discussions.

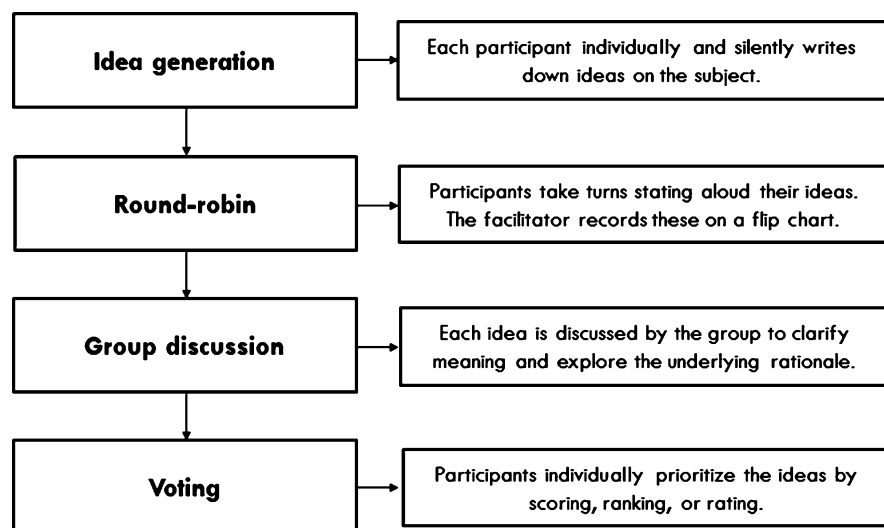


Fig. 1 The four phases of the nominal group technique

3.3 Conducting the Nominal Group Technique

The NGT typically lasts between 60 and 90 minutes and involves four phases detailed in the following section and summarized in Fig. 1:

1. **Silent generation of ideas:** The facilitator presents the question to the group and directs the participants to individually and silently write down their responses and ideas. Participants are given anywhere from 5 (Aspinal et al. 2006) to 20 minutes (Claxton et al. 1980) to generate ideas, and during this time the participants and facilitator remain silent.
2. **Round-robin recording of ideas:** Participants are asked one at a time to contribute a single idea to the group which the facilitator then records on a flip chart (or similar), which is visible to the whole group. The round-robin proceeds until all participants have stated their ideas and there are no new ideas being generated, or when the group determines that a sufficient number of ideas have been produced. Comments and discussion from participants at this stage are not recommended but may be appropriate or necessary depending on the group (McMillan et al. 2014, 2016).
3. **Discussion of ideas:** This phase of the NGT involves a group discussion on each of the ideas listed on the flip chart. It provides an opportunity for participants to clarify and express their understanding and opinions of the ideas, as well as to explore the rationale underlying their perspectives. Throughout the discussion, the group may decide to add, alter, or group similar ideas together. The facilitator

must ensure that all ideas are discussed and that participants have a full understanding of each of the ideas, to enable them to make informed decisions in the voting process. Moreover, the facilitator should emphasize that participants do not have to agree with all the ideas and that their personal preferences will be recorded in the next phase of the NGT. Researchers should note that the use of audio recordings during this phase is usually required for qualitative data analysis but may be refused by some participants.

4. **Voting:** The voting phase consists of participants individually prioritizing the ideas based on what they believe to be most important. There are a number of ways to conduct this process, which include scoring, ranking, or rating the ideas. For example, participants may be asked to select between five and ten of their most important ideas from the list and then to rank them in order of importance. The number of items to be ranked depends on a range of factors, including the study topic and aims, total number of ideas generated, and participant ability and willingness; however the literature commonly reports the use of five items (Delbecq et al. 1975; Denning et al. 2013; McMillan et al. 2014). Variations of prioritizing may include each participant ranking the entire list of ideas, with the most important idea ranked one, the next ranked two, and so on. Other variations may involve scoring, such as each idea being scored a number from one to five (Vander Laenen 2015). Depending on the desired anonymity of the voting process, participants may share their votes with the group and the facilitator may tabulate these on the flip chart to be discussed by the group.

3.4 The Modified NGT

The NGT is a highly adaptable method and is commonly used by researchers to inform, or in combination with, other qualitative (e.g., interviews or focus groups) and quantitative (e.g., discrete choice experiment) methods (see also ► Chaps. 23, “Qualitative Interviewing,” and ► 36, “Eliciting Preferences from Choices: Discrete Choice Experiments”). A combined nominal group/focus group technique has frequently been used (Howell et al. 2012; Urquhart-Secord et al. 2016) and combines the prioritization process of a standard NGT with the in-depth discussion of a focus group. This approach is considered beneficial as it allows for further exploration and discussion of ideas (Varga-Atkins et al. 2017).

Hilgsmann et al. (2013) conducted a NGT to identify and select attributes for inclusion in a discrete choice experiment. Participants were asked to rank the list of attributes in order of importance from 1 (most important) to 12 (least important). New or missing attributes could also be included by participants. In this study, the traditional first phase of silent generation of ideas by participants was not included because the researchers had already identified ideas from the literature.

Typically, the phases most commonly modified in the NGT are phase one (silent generation of ideas) and phase four (voting). As demonstrated in the study by

Hilgsmann et al. (2013) described above, phase one may not involve the generation of ideas by participants. Instead, ideas may be obtained by the researchers prior to the NGT from a literature review or survey (Vella et al. 2000). Examples of variations in phase four have been highlighted in the section above.

Some studies have also conducted phases two (round-robin) and three (discussion of ideas) simultaneously. For example, McMillan et al. (2014) conducted a NGT with Aboriginal and Torres Strait Islander people and found it was culturally appropriate for discussion among participants to occur during the round-robin, as it helped to create a safe and supportive environment for participants. Ultimately, the NGT may need to be modified to suit the participant needs, logistics, and research aims.

3.5 Data Analysis

The NGT elicits both qualitative and quantitative data through the group discussions and voting process, respectively. Qualitative data analysis for NGT typically aims to provide context and rationale for the generated and prioritized ideas. This involves an interpretive and iterative process of data reduction in which meaningful sections of data (i.e., the transcribed group discussions) are coded into concepts. Codes serve as a way to summarize and organize the data and may be grouped together to develop themes (see ► Chaps. 47, “Content Analysis: Using Critical Realism to Extend Its Utility,” and ► 48, “Thematic Analysis”). Researchers may use qualitative data management software (e.g., HyperRESEARCH, NVivo, ATLAS.ti) to code, organize, and retrieve data (see ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). The qualitative data can be compared to the priority scores (quantitative data) and used to contextualize and justify group priorities (McMillan et al. 2014). Quotations from individual participants can be presented to help provide explanations for individual and group priorities (Potter et al. 2004).

Quantitative data analysis depends on the way the voting process was conducted (i.e., ranking, rating, or scoring). In general, the data processing and analysis of NGT quantitative data is relatively simple, as a summary of the group priorities may be generated by the facilitator during the session (Aspinal et al. 2006; Vander Laenen 2015). Following the NGT, researchers will usually input the raw data (i.e., individual participant votes) into an Excel spreadsheet to calculate the priority of each item. For example, this may be done by summing the scores for each item (Aspinal et al. 2006), or calculating a mean rank score based on the number of participants who ranked the item (Urquhart-Secord et al. 2016). It is suggested that items should be assessed in terms of the score as well as the frequency of votes, as this may be more representative of priorities (McMillan et al. 2014). If multiple NGT sessions are conducted for the same research question, group scores can be collated to give an overall priority of items (Denning et al. 2013). If participant details are collected and can be linked to the individuals’ votes, analysis can be performed to compare across participant characteristics (e.g., gender, age, ethnicity) (Vander Laenen 2015).

In a proposal to use NGT to develop core outcomes in polycystic kidney disease, Cho et al. (2017) report methods of quantitative data analysis to generate a measure of importance (i.e., importance score). The importance score is a summary measure of the importance of each outcome that incorporates the consistency of being nominated and the rankings given by participants. To calculate this measure, the distribution of the ranking for each outcome was obtained by calculating the probability of each rank for each outcome: $P(O_j \text{ in rank } i)$, i.e., the probability of the outcome O_j being assigned the rank i . Hence for each outcome, they obtained the probability of being ranked in first place, second place, and so on. By the total law of probabilities, the probabilities are decomposed as:

$$P(O_j \text{ in rank } i) = P(O_j \text{ in rank } i \mid O_j \text{ is nominated}) \times P(O_j \text{ is nominated}) \\ + P(O_j \text{ in rank } i \mid O_j \text{ not nominated}) \times P(O_j \text{ not nominated})$$

where “nominated” means that the outcome was ranked by the participant. This assumes that the $P(O_j \text{ in rank } i \mid O_j \text{ not nominated})$ is 0. The reasoning behind this is if the participant did not mention the outcome O_j , then the probability of any rank is 0. Therefore, the expression above simplifies to

$$P(O_j \text{ in rank } i) = P(O_j \text{ in rank } i \mid O_j \text{ is nominated}) \times P(O_j \text{ is nominated})$$

From this expression, the probability has two components: (1) the importance given to the outcome by the ranking and (2) the consistency of being nominated by the participants. These probabilities and the computed weighted sum of the inverted ranking ($\frac{1}{i}$) are used to obtain the importance score (IS).

$$\text{IS} = \sum_{i=1}^{\text{nr of outcomes}} P(O_j \text{ in rank } i) \times \frac{1}{i}$$

The reason for inverting the ranks is to give more weight to top ranks and less to lower ranks. Higher values of the score identify outcomes that are more valued by the participants. The standard errors for the importance score could be obtained through bootstrapping. This measure proposed by Cho et al. (2017) has a similar motivation to the Expected Reciprocal Rank Evaluation Metric proposed in a different context (Chapelle et al. 2009).

4 Advantages and Disadvantages of the NGT

Using the NGT allows researchers to explore a range of ideas generated by participants with expertise or experience in the proposed topic or question in a relatively short timeframe with little or no preparation required by participants. The combination of silent idea generation followed by discussion enables broad generation of

ideas while reducing direct criticism and simultaneously allowing for clarification and definition of ideas. The primary strength of the NGT is the structure of the group which ensures equal participation by each member and prevents dominant or outspoken participants from controlling the discussion, resulting in a balance of influence (Carney et al. 1996). This strength, however, relies on the skill of the facilitator to effectively moderate the group discussion as explained above. The NGT may also be more suitable compared to other consensus methods, such as the Delphi technique, for people who may feel more comfortable participating in an in-person meeting than in a relatively complex multi-round survey (McMillan et al. 2016). Unlike the Delphi technique, the NGT enables the opportunity to explore reasons for disagreement in opinions through group discussion, and participants can revise their views by exploring and considering the opinions of others (Allen et al. 2004; see also ► Chap. 41, “The Delphi Technique”). Finally, the NGT process can be adapted to accommodate participant needs such as low health literacy, and group moderation by facilitators can ensure that all voices are heard (McMillan et al. 2014).

One disadvantage of NGT is that this method is suited to addressing only one idea or question at a time, thereby limiting the ability to foster new ideas which participants may consider to be important. Additionally, the structured format may be less stimulating than other group techniques and may minimize discussion and generation of ideas. Moreover, while this technique is effective in generating consensus among a group, this does not always equate with the “correct” answer to the research question. This technique, therefore, may be best suited to eliciting expert perspectives on their own experiences and priorities. Finally, this technique requires extensive planning and preparation. Participants must be recruited and attend in-person, which may be burdensome and ultimately lead to nonattendance. For example, Rupert et al. (2017) conducted a study comparing differences in recruitment and logistics between in-person and online focus groups. The authors found that in-person groups were less geographically diverse, and more likely to be white, more educated, and healthier. Despite the fact that sampling methods – specifically purposive sampling – can be applied to capture a broad range of participants, the study by Rupert et al. (2017) reveals that some limitations remain which may have implications for the group dynamics as well as the findings. In view of this, some authors propose that the findings from consensus methods are not a definitive end point but rather an exploratory initial step requiring further investigation (Jones and Hunter 1995). The advantages and disadvantages of the NGT are summarized in Table 1.

4.1 Considerations for Involving Patients in NGT

While it is widely acknowledged that it is important to involve patients and caregivers in research, the impact of this involvement on the participant is sometimes overlooked. Some participants may value the opportunity to share their personal experiences and to meet other people with similar conditions. However, other participants may feel confronted by topics or outcomes relating to their condition

Table 1 Advantages and disadvantages of the nominal group technique

Advantages	Disadvantages
Utilizes informed expert panel	Addresses a single idea/question
Neutralizes dominant participants	Potential for selection bias
Encourages equal representation	Consensus does not equal “correct” answer
Reduces direct criticism and rejection	Benefits rely on facilitator skills
Allows time to generate ideas individually in silence	Resource and time intensive
Allows for clarification and definition of ideas	
Time efficient	

that they may not have been aware of previously. Due to the heterogeneity of symptom presentation in some health conditions, it may be helpful to select participants who are at similar stages of the disease to ensure that they feel the process is relevant to them. As participants may discuss issues relating to medical treatments, it is important to clarify that the NGT is not a forum for medical advice or recommendations and that participants should clarify any concerns that may have been raised in the discussion with their treating physicians. Researchers should consider how the research question and participant selection may impact participants emotionally and psychologically and ensure that participants have access to support following the NGT to address any issues that may have emerged in the discussions.

5 Conclusion and Future Directions

The purpose of this chapter was to outline the utility of the NGT, to review the advantages and disadvantages of using this technique, and to provide an overview of methods for conducting NGT, including participant recruitment and sampling, data collection, and analysis. This section briefly discusses potential future applications of this research method.

Online group techniques are commonly used throughout health and social research (see, e.g., [Tates et al. 2009](#); [Thomas et al. 2013](#); [Howells et al. 2017](#)), though very few have involved NGT. In view of its adaptability, the NGT could be applied online to address the challenges inherent to in-person groups. Benefits include the ability to access hard-to-reach populations, such as those who live outside of metropolitan areas, or those with severe disabilities who are unable to travel. Furthermore, online and anonymous NGT may be more appropriate and elicit greater participation than in-person groups for sensitive topics such as sexual health and behavior, illicit drug use, and violence. For example, [Woodyatt et al. \(2016\)](#) conducted a study comparing the quality and depth of data generated from in-person versus online focus groups. The study recruited gay and bisexual men and compared the data from two online and two in-person focus group discussions on the topic of intimate partner violence. The findings revealed that the online groups provided

responses which were more succinct and relevant to the research question and were without the interruption experienced during in-person groups. However, the frequency of intragroup conflicts (including disagreement and insults) was greater in the online groups. The facilitator, therefore, has an important role to ensure a safe and supportive environment for participants in this setting. Overall, the content and quality of the data from the two settings was found to be equivalent (see also Kramish Campbell et al. 2001; Synnot et al. 2014).

The NGT is a useful method to generate a large amount of qualitative and quantitative data regarding the preferences and priorities of its participants. The flexibility of the technique enables it to be modified to suit the needs of participants and researchers, and it functions both as a stand-alone technique and within a mixed methods study design.

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Jumping the Methodological Fence: Q Methodology

43

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Contents

1	Introduction	752
2	What Is Q Methodology?	753
3	Developing a Study Using Q Methodology	754
3.1	Concourse Development	754
3.2	Item Sampling: Q Set	755
3.3	Selection of Participants: The P Set	755
3.4	Q Sorting: Techniques for Collecting Q Data	756
3.5	Process of Analysis and Factor Interpretation	757
4	Strengths and Limitations of Q Methodology	762
5	Q Methodology in Action	763
6	Conclusion and Future Directions	764
	References	766

Abstract

Mixed methods research is consistently used quantitatively and qualitatively to understand and explore the many facets of a range of phenomena. Generally, mixed methods research involves the use of qualitative and quantitative methods simultaneously or concurrently, yet for the most part independently. What if these methods could be truly mixed? This chapter introduces readers to a methodology that aims to address this question – Q methodology. Q methodology allows for the sampling of subjective viewpoints and can assist in identifying patterns,

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including areas of difference or overlap, across various perspectives on a given phenomenon. Q methodology can be described as “‘qualiquantillogical’ combining elements from qualitative and quantitative research traditions” (Perz et al. BMC Cancer 13: 270, 2013, p. 13). This chapter will outline the five steps involved in conducting a Q methodology study: (1) developing the concourse, (2) developing the Q set, (3) selection of the P set, (4) Q sorting, and (5) Q analysis and interpretation. In order to contextualize and demonstrate how Q methodology can be used, we will present reflections on the use of this methodology with respect to constructions of sexual and reproductive health, chronic low back pain, and culturally and linguistically diverse people. These examples demonstrate how Q methodology can provide a unique and truly mixed way of studying human subjectivity.

Keywords

Q methodology · Social research · Health research · Mixed methods · Subjectivity

1 Introduction

Mixed methods research involves the collecting, analysis, and interpretation of both quantitative and qualitative data in a singular study or series of studies (Creswell and Plano Clark 2018). The use of both qualitative and quantitative methods to answer a research question is central to the concept of mixed methods research which maximizes the strengths and minimizes the weaknesses of employing a single approach (2011). In order for a study to be considered mixed methods, there should be a clear integration of approaches at the design, analysis, or interpretation stages of the project (Fetters et al. 2013).

A fundamental assumption behind mixed methods is that it can address research questions more comprehensively than employing qualitative or quantitative approaches alone (Creswell and Plano Clark 2018). Broad and complex research questions with multiple aspects that are difficult to address using either a qualitative or quantitative approach are appropriate for a mixed methods investigation (Tashakkori and Teddlie 2010). Usually, quantitative research is used to assess the magnitude of concepts or constructs or test a hypothesis, while qualitative studies are associated with exploring the meanings of complex social or cultural concepts including how and why people think in a certain way (see ► Chaps. 2, “Qualitative Inquiry,” and ► 3, “Quantitative Research”). Combining the two approaches in a study has the potential to allow for a broader examination of the study phenomenon (see ► Chap. 4, “The Nature of Mixed Methods Research”).

Mixed methods researchers suggest several reasons for combining qualitative and quantitative data which include:

- Complementary: Findings from one method can be used to explain results from another. For example, Tariq et al. (2012), in their mixed methods study of the

impact of African ethnicity and migration on pregnancy, identified potential disparities in health-care access and outcomes by analyzing a national surveillance data. Then, semi-structured interviews with pregnant African women allowed them to understand factors driving the disparity.

- **Development:** Results from one study can be used to inform the development of the other. For instance, Stoller et al. (2009) conducted a qualitative study first to identify factors contributing to the reduction of alcohol use in hepatitis C-positive patients. A quantitative survey was then conducted to quantify and test the identified factors.
- **Triangulation:** Data obtained from both methods can be used to corroborate findings. Mengesha et al. (2017) used a survey to measure health-care professionals' knowledge, skills, and attitude to provide sexual health care to refugee and migrant women. Semi-structured interviews with health-care providers were conducted to confirm survey findings.
- **Expansion:** Examine several research questions in a study using different methodologies. For instance, Montgomery et al. (2010) conducted a randomized control trial to assess the efficacy of a vaginal microbicidal gel on vaginal HIV transmission and in-depth interviews with trial participants to assess the acceptability of the gel.

Although mixed methods research has several benefits, there are also some challenges that should be noted (Tariq and Woodman 2013). For instance, the collection, analysis, and interpretation of multiple forms of data require extensive resources and time and involve skills and experiences in both qualitative and quantitative approaches (Tariq and Woodman 2013; Creswell and Plano Clark 2018). This suggests that a well-working team from different disciplines is required for a rigorous conduct of mixed methods research. Interpreting the findings of a mixed methods study can also be challenging as investigators may place unequal weight in relation to the depth of the data and accuracy, validity, and theoretical emphasis of each data set (Creswell et al. 2011; Tariq and Woodman 2013). (See also ► Chaps. 4, "The Nature of Mixed Methods Research," ► 39, "Integrated Methods in Research," and ► 40, "The Use of Mixed Methods in Research.")

2 What Is Q Methodology?

Q methodology is derived from a range of earlier and similar ranking techniques including Kelly's repertory grid methods (Robbins and Krueger 2000) to aid researchers in "revealing the subjectivity involved in any situation" (Brown 1993, p. 561). The term Q methodology was coined by Stephenson in the 1950s. Q methodology allows for the sampling of subjective viewpoints and can assist in identifying patterns, including areas of difference or overlap, across various perspectives on a given phenomenon (Watts and Stenner 2012). Q methodology can be described as "'qualiquantillogical' combining elements from qualitative and quantitative research traditions" (Perz et al. 2013, p. 13). The data is composed of participant's constructions of a specific topic, obtained by ranking a set of predefined items according to their experiences, understandings, and perspectives. The factors

resulting from factor analysis represent constructions of subjectivity that are present within the rankings (Brown 1993). In Q methodology, a factor analysis is performed to identify associations between patterns expressed by participants, a procedural inversion to conventional factor analysis that is used to identify associations between variables (Lazard et al. 2011). As such, the focus in Q methodology is not the “constructors” (the participants) but the “constructions” themselves (Rogers 1995).

Q methodology has been described as a more robust technique than alternative methods for the measurement of subjective opinions and has been recommended in the study of attitudes within the health field (Cross 2005). In the area of health and well-being, previous authors have also used this approach to examine constructions of sex and intimacy after cancer (Perz et al. 2013), explore constructions of bulimia (Churruca et al. 2014), investigate understandings of irritable bowel syndrome (Stenner et al. 2000), examine beliefs about the sexuality of the intellectually disabled (Brown and Pirtle 2008), and explore experiences of postnatal perineal morbidity (Herron-Marx et al. 2007).

3 Developing a Study Using Q Methodology

Watts and Stenner (2012) have captured five primary steps in conducting a Q methodology study. These include (1) developing the concourse, (2) developing the Q set, (3) selection of the P set, (4) Q sorting, and (5) Q analysis and interpretation.

3.1 Concourse Development

The first step in conducting a Q methodological study is generating a “collection of all the possible items the respondents can make about the subject at hand” called a concourse (Van Exel and de Graaf 2005). A concourse represents all the things people think or say about the subject being studied. Researchers commonly use statements of opinion (verbal concourse), although other items such as paintings, photographs, musical selections, and pieces of art can be used in Q methodology (Brown 1993; Paige 2014). Developing an effective concourse can begin with a comprehensive review of literature or media from different sources. A literature review can be conducted to explore and analyze existing evidence concerning the phenomena in question. Online and other media can also be explored to identify relevant constructions of phenomena to help draw out statements to add to the initial concourse (Brown and Pirtle 2008).

Concourse can also be developed by eliciting statements from key informants who can provide their perspectives on the issue in question to make sure that the statements within the concourse represent the views of people who may be part of the sample. This approach also allows the researcher to develop a concourse that covers perspectives from a range of stakeholders (Perz et al. 2013). Such stakeholder can include experts in academic or practical areas surrounding the phenomena in question. Qualitative methods are helpful in this regard as they assist in drawing out

the why, how, and what of a particular topic of interest (Liamputtong 2013; see also ► Chap. 2, “Qualitative Inquiry”). In the case of interviews, for example, these can be audio-recorded, transcribed verbatim, and then the transcripts can be examined for statements to be included in the concourse (see ► Chap. 23, “Qualitative Interviewing”). Key informants can also assist in reviewing the statements collated in the concourse and give feedback on how the statements could be amended in order to better reflect a representative sample of perspectives.

3.2 Item Sampling: Q Set

The Q set is a representative sample of the concourse provided to participants for rank ordering (Brown 1993). The Q set results from deconstructing relevant topics into a series of sub-themes and in line with the research question (Watts and Stenner 2012). This helps to ensure that all aspects of the subject of interest are covered and items are not inclined toward a particular viewpoint (Coogan and Herrington 2011). The refinement process of statements within each of the themes continues until a final set of items is ready for administration. Through the process, statements can be revised, duplicate items discarded, and additional items added. The resulting set can then be piloted with key and expert informants. Based on their feedback, the pool is then reduced to a final set of statements that broadly represents a range of viewpoints. Although the number of statements can vary depending on the study question, sample, and other logistical variables, Rogers (1995) has suggested that a Q set with more than 60 statements can result in participant fatigue and therefore disengagement with statements after this point.

3.3 Selection of Participants: The P Set

Unlike survey studies (see ► Chaps. 32, “Traditional Survey and Questionnaire Platforms,” and ► 76, “Web-Based Survey Methodology”), the emphasis of a Q methodological study is not on the number of people who think in certain ways; rather it is focused on why and how people may present a particular way of thinking about the study topic. Therefore, studies involving Q methodology use relatively small sample sizes (Brown 1993; McKeown and Thomas 1988). According to Rogers (1995), a group of 40–60 participants is enough to establish the existence of particular viewpoints. Watts and Stenner (2012) suggest strategic selection of the participants in order to achieve a broad sample that can give the best insights about the topic.

3.4.2 Electronic Techniques

Online Q sorting generally requires participants to complete the sorting in three phases – similar to that of the manual process described above. Online or software-based Q data collection methods can reduce the time and expense sometimes required for manual data collection. Further, online programs like Q-Assessor reduced the difficulty and complexity of manual analysis for researchers. From the mid-1990s, some primary data collection solutions have been developed; in particular WebQ helps to collect the Q sorts online, and Q-Assessor allows for the collection and analysis of Q sort data (Reber and Kaufman 2011).

The Example of Q-Assessor

Q-Assessor is a paid service for a simple web-based sorting technique, suitable for users who can access the Internet (Omeri et al. 2006). It helps the investigator to configure the different parts of the Q study, collect and analyze data, and engage with participants (Reber and Kaufman 2011). It has been validated against the more traditional manual Q sort collections (Reber et al. 2000), and its use is increasingly growing for the following reasons: (i) it allows easily to first cluster the statements into the “agree,” “neutral,” and “disagree” bins and then to proceed with the final ranking on the grid; (ii) allows participants to change their mind at any time; (iii) helps to sort the statements starting from the extremes, firstly ranking the “mostly agree,” then “mostly disagree,” and then “neutral” statements; (iv) collects other information, such as post-sort comments; (v) automatically sends results to the investigator who can check in real time the ongoing development of the study (i.e., if the subject has started and/or completed the Q sort); (vi) manages participant recruitment, including automatic reminders and post-completion communication; and importantly (vii) performs data analysis.

3.5 Process of Analysis and Factor Interpretation

The main objective of Q analysis is to identify viewpoints or perspectives shared by participants where these shared views are represented by factors. This is achieved by performing a by-person factor analysis – a commonly applied statistical method in Q methodology. Factor analysis begins with the calculation of correlation matrix that reveals the degree of agreement or disagreement between the sorts or the similarity or dissimilarity in the views of the Q sorters. From this matrix, the centroid method can be used to extract initial sets of factors. This method is preferred by most Q methodologists (Brown 1993; Watts and Stenner 2012) as it allows the researcher to explore the data through rotation until the best factor solution is achieved (Watts and Stenner 2012). The extracted factors should then be subjected to varimax rotation: a statistically and theoretically sound method for factor rotation. In Q analysis, varimax positions factors so that the overall solution maximizes the amount of study variance explained (Watts and Stenner 2012). It also gives a very workable factor solution considering the majority viewpoints of the study participants (Watts and Stenner 2012). Following rotation, factors for interpretation will be selected if they fulfilled the stringent criteria of at least two sorts significantly loading upon a factor and

eigenvalues greater than one (Watts and Stenner 2005). At this stage, factors should also be examined if they reveal a distinct and meaningful viewpoint. The nature of the research topic may also influence our decision regarding the number of factors that should be retained for interpretation. For instance, Mengesha et al. (2017) chose a broad factor solution that gives a larger number of factors to capture the complexity of engaging refugee and migrant women in sexual and reproductive health in salient and clear ways.

Before starting factor interpretation, a factor array (see Table 1 Q-set statements and factor array) will be created for the factors to facilitate factor interpretation. A factor array is where each of the factors is represented by its own “best-estimate Q sort or ‘factor array’... These factor arrays or best-estimate Q sorts can then be subjected to interpretation” (Watts and Stenner 2005, p. 82). The interpretation can be done by reading the statements thematically and analyzing their position relative to all other statements within individual factors. In the process of interpretation, attention is given to the whole configuration of items in a factor with the aim of achieving holistic factor interpretations. Statements that have statistically different factor scores across factor arrays (distinguishing) are then examined to clarify the difference between factors. For those participants whose responses load significantly onto a factor, responses to auxiliary questions and demographic data can be examined to assist in identifying the meaning of each factor.

3.5.1 Tools to Assist with Analysis

Traditional statistical software (i.e., SPSS) can be used for analysis but are not preferred due to syntax adjustments required during factor analysis. There are other Q methodological packages available that can be used for data analysis and generate the by-person correlation matrix and factor extraction (Watts and Stenner 2005). These also offer the centroid method as default choice that provides an unlimited number of rotated solutions (Watts and Stenner 2005). PCQ for Windows and PQMethod are the most recommended and dedicated packages for Q analysis, and the latest versions can be downloaded from (<http://schmolck.userweb.mwn.de/qmethod/>).

3.5.2 Data Analysis with Q-Assessor

Once all data has been collected, the Q-Assessor performs the analysis based on data extraction techniques described by Brown (1980) but also allows investigators to manipulate their data on their own computers. Q-Assessor analysis conducts correlation matrix, provides unrotated and rotated factors flagging the significant responses, and provides the possibility to download the reports: (i) rank statement totals for each factor, (ii) normalized factor scores, (iii) comparisons between factor scores, (iv) Q sort values for each statement, (v) distinguishing and consensus statements for factors, and (vi) factor characteristics. Notably, Q-Assessor allows also to detect the participant linked to his/her Q sort and to the open-ended comments. Information regarding how to use Q-Assessor is available at q-assessor.com (<http://q-assessor.com>).

Table 1 Q-set statements and factor array for a study on the sexual and reproductive health and help-seeking among 1.5 generation migrants

	Q-set statements							
	Factor							
		A	B	C	D	E	F	G
1	If my family or community found out that I had a sexually transmitted infection, they would not be very supportive	2	0	-1	0	1	1	-2
2	I would never let my family or community know that I had sex outside of marriage	1	3	-2	-2	1	4	1
3	If I had a sexual and/or reproductive health issue, I would have to find a way to go to a clinic without my family or community knowing	-3	2	0	-1	0	2	-2
4	If my family or community found out that I was involved in an unplanned pregnancy, they would not be very supportive	-1	-2	-2	-1	2	-1	2
5	If I had a sexual and/or reproductive health issue, other people's perceptions about it would impact how and when I got professional help	2	1	2	-3	1	0	2
6	Going through adolescence and puberty was sometimes difficult because the things I was taught at school or in the media about sexual and reproductive health were different to what my family or community believe	1	0	-2	0	-3	3	0
7	People who move from one country as children and grow up in Australia are often confused about sexual and reproductive health	0	0	4	0	-1	0	-1
8	I want to pass on to future generations the values about sexual and reproductive health held by my culture of origin	-3	-3	3	0	2	-1	2
9	The way that sexual and reproductive health is dealt with in Australia is very different than the way it is understood in the country where I was born	1	-3	1	0	1	3	1
10	In my origin culture, openly discussing sexual and reproductive health is encouraged	-2	-4	2	2	-3	-3	-1
11	In my origin culture, women have control over their sexual and reproductive health	-4	0	1	1	1	-3	3
12	In Australia people are encouraged to discuss sexual and reproductive health	-2	-1	3	3	4	3	4
13	People who were born in Australia have an easier time with sexual and reproductive health than migrants like me	1	-2	1	2	4	-1	-1

(continued)

Table 1 (continued)

	Q-set statements							
	Factor	A	B	C	D	E	F	G
14	Australians can have intimate relationships with whomever they like, and no one would mind	0	2	2	3	-1	0	3
15	Culture plays a large role in how people experience sexual and reproductive health	1	3	-1	4	2	4	0
16	Sexual and reproductive health in my culture of origin is a taboo subject	4	1	1	-3	0	1	-4
17	Australia is very conservative about sexual and reproductive health	-1	1	-3	-2	-2	-1	3
18	In my origin culture, sexual and reproductive health is perceived of more in terms of women's or men's health	0	1	-1	0	1	1	-1
19	I avoid casual sexual encounters because my family or community would think I was disrespecting my origin culture	0	2	-2	-4	3	2	0
20	Australian men and women think of sexual and reproductive health in the same ways	3	-2	-1	1	-1	-1	-3
21	Australian values lead my understanding of sexual and reproductive health	-3	-1	-4	2	-1	2	-2
22	Sexual and reproductive health refers mostly to the prevention of and protection from disease	0	4	-3	1	0	-2	-2
23	Sexual and reproductive health refers mostly to means prevention of unplanned pregnancy	-2	-4	0	-1	-2	-3	0
24	Sexual and reproductive health refers mostly to contraception	2	0	-4	-1	-2	-4	-3
25	Sexual and reproductive health is usually something only promiscuous people have to deal with	-4	1	0	-3	-4	-4	1
26	The way that sexual and reproductive health is understood in Australia is very different than the way it is understood in the country where I was born	1	-1	3	-1	3	2	0
27	There are no words in my culture of origin for sexual and reproductive health	-1	-1	2	-1	-1	0	-4
28	Culture plays a large role in how people understand sexual and reproductive health	3	-1	4	4	2	2	2
29	Health-care workers are well equipped to deal with the sexual and reproductive health needs of people from my background	1	0	1	1	0	-2	-1
30	Australians can more easily get help for sexual and reproductive health issues than people from my culture of origin	2	-1	-2	1	3	0	1

(continued)

Table 1 (continued)

	Q-set statements							
	Factor							
		A	B	C	D	E	F	G
31	Migrants need more assistance from health services with sexual and reproductive health than people born in Australia	-2	0	1	3	-1	1	0
32	Health-care workers have very little knowledge of the beliefs related to sexual and reproductive health within my culture	0	-3	-3	1	0	0	-2
33	Health services provide the anonymity needed to cater to migrants sexual and reproductive health needs	-1	2	0	1	2	1	0
34	Health services provide clients with a choice between a male or female health-care provider	-1	2	0	0	0	0	-3
35	Health services cannot do much else to better cater to the sexual and reproductive health needs of migrants	-2	1	0	0	-1	-2	-1
36	Migrants who identify most as being Australian have more sexual and reproductive health issues than other Australians (excluding Aboriginal and Torres Strait Islander peoples)	-1	3	-1	-2	0	-1	0
37	Migrants who identify most with their culture of origin have more sexual and reproductive health issues than other Australians (excluding Aboriginal and Torres Strait Islander peoples)	0	0	1	-2	-4	-1	1
38	Migrants from certain cultures are carriers of sexually transmitted infections	2	-2	2	-4	-2	-2	-1
39	Migrants who do not take on Australian ways of understanding sexual and reproductive health have failed to assimilate	-1	-1	0	-2	-2	-2	1
40	Australians should take on more values about sexual and reproductive health from migrant cultures	0	4	0	2	-3	1	1
41	Migrant sexual and reproductive health needs are quite different from those of nonmigrants	3	-2	-1	-1	0	0	2
42	Australians may think that some migrant groups have outdated ideas about sexual and reproductive health	4	1	-1	2	1	1	4

4 Strengths and Limitations of Q Methodology

Q methodology is a unique research method that identifies commonalities and divergences within and between groups. It combines strengths from quantitative and qualitative research methods (Ellingsen et al. 2010), using a systematic approach to analyze the Q sorts but providing an interpretation that is typical of qualitative research methods. Q methodology reveals subjectivity that is particularly important in complex contexts, such as social and health fields.

In Q methodology, user participation is the main focus and strength for different reasons. Firstly, the concourse is developed using information deriving from interviews and group discussions provided by participants on the topic of interest. As a consequence, researcher's preconception is minimized (Corr 2006). Secondly, shared viewpoints are gained through factor analysis of the Q sorts based on participants' perspectives, and the forced distribution, used to collect Q sorts, helps to reduce the number of uncertain statements and decide the most important ones (Cross 2005).

Q methodology is an easy-to-use method where participants do not necessarily need to verbalize about sensitive topics. Therefore, it can be considered as a non-threatening means to gather personal viewpoints. Q methodology has also the advantage to enhance the level of participants' inclusion. In fact, as statements can be pictures, images, or even single words, individuals with a wide range of ages and social and physical conditions (including children or people with learning disabilities) can actively take part and provide their stories (Ellingsen et al. 2010).

Q methodology also has some limitations. One of the main ones is that developing the concourse can be time-consuming, for example, when interviews and group discussions needed to be conducted to gather more information on the topic of interest. Secondly, the sorting activity and the extensive explanations provided to instruct participants on how to use the method are also time-consuming, and the lack of comprehension on how to participate can affect the validity of results.

Further, Q methodology has received some critics regarding how results are obtained: reliability has been questioned as repeating the method on the same participant does not necessarily yield the same viewpoints (Cross 2005). However, few studies have demonstrated that administering the same Q sample to the same participants at two different time points resulted in correlation coefficients between 0.80 and 0.95 (Fairweather 1981).

Another limitation is that the expression of participants' subjectivity is limited by sorting predetermined statements, chosen by the researcher. However, using interviews or group discussion to gather information for the statements' development helps to alleviate this limitation. Participants' free expression is also limited by the "forced choice" of the sorting activity. On the other hand, some authors argue that the unforced choice risks to produce less discrimination than forced methods, which would make assessment and interpretation more difficult (Dziopa and Ahern 2011).

Finally, regardless the sample size, in Q methodology, results cannot be generalized in that they are limited to the participants' viewpoints of that particular study, nor researchers can claim that all potential viewpoints on the topic of interest are elicited (Dziopa and Ahern 2011).

5 Q Methodology in Action

We have conducted studies using Q methodology as a primary investigator, and these example studies are used to illustrate how Q methodological study can be done including the pros and cons for each project. Dune et al. (2017) investigated the role of culture in constructions of SRH from the perspective of 1.5 generation migrants (those who migrate as children or adolescents). Forty-two adults from various ethno-cultural backgrounds rank-ordered 42 statements about constructions of SRH and SRH help-seeking behavior. A by-person factor analysis was then conducted, with factors extracted using the centroid technique and a varimax rotation. A seven-factor solution provided the best conceptual fit for constructions of SRH. Factor A compared SRH values within Australia and migrants' culture of origin. Factor B highlighted the influence of culture on SRH values. Factor C explored migrant understandings of SRH in the context of culture. Factor D explained the role of culture in migrants' intimate relationships, beliefs about migrant SRH, and engagement of health-care services. Factor E described the impact of culture on SRH-related behavior. Factor F presented the messages migrant youth are given about SRH. Lastly, Factor G compared constructions of SRH across cultures.

Mengesha et al. (2017) also conducted a Q methodological study to identify the challenges of providing sexual and reproductive health care to refugee and migrant women. Forty-seven health professionals rank-ordered 42 statements and commented on their rankings in subsequent open-ended questions. Seven factors each with a distinct and meaningful viewpoint were identified. These factors are "communication difficulties – hurdles to counseling," "the lack of access to culturally appropriate care," "navigating SRH care," "cultural constraints on effective communication," "effects of the lack of cultural competency," "impacts of low income and language barrier," and "SRH services are accessible, but not culturally relevant."

Buscemi et al. (2018) used Q methodology to identify shared perspectives on day-to-day stressors in people experiencing chronic low back pain. Fifty statements representing the broad experience of psychosocial stress were ranked and sorted using a predefined quasi-normally distributed grid by 61 participants. A by-person correlation and factor analysis revealed seven factors corresponding to seven different group viewpoints (Groups 1–7). Viewpoints were enriched using standardized questionnaires to identify the presence of distress (DASS-21), stress (PSS), pain self-efficacy (PSEQ), and pain catastrophizing (PCS). Only in one group (Group 1) did participants demonstrate a sense of mastery over their life and

chronic pain condition (“I’ve learned to live with the pain, so it doesn’t stress me out”). In Groups 2 and 3, the main focus of stress was the perceived limitation and life disruption caused by living with CLBP (“I feel unwell all the time”). In Group 4, stress manifested as an overwhelming force, associated with a feeling of being trapped by having too many responsibilities in life (“The more stress, the more often I have back pain”). In Groups 5 and 6, participants felt stressed by worries and demands from the outside world including family, work, and recent changes in living conditions (“Children, health problems, full time work”). In Group 7, stress resulted from personal fears and worries coupled with low self-esteem that impacted on participants’ perceptions of themselves and the world around them (“Not feeling appreciated or valued”).

Finally, Perz et al. (2013) explored the complex perspectives that people with personal and professional experience with cancer hold about sexuality in the context of cancer. Participants were asked to rank-order 56 statements about sexuality and intimacy after cancer and asked to comment on their rankings in a subsequent semi-structured interview. A by-person factor analysis was performed with factors extracted according to the centroid method with a varimax rotation. A three-factor solution provided the best conceptual fit for the perspectives regarding intimacy and sexuality post-cancer: Factor 1, entitled “communication – dispelling myths about sex and intimacy;” Factor 2, “valuing sexuality across the cancer journey;” and Factor 3, “intimacy beyond sex.”

Table 2 presents the pros and cons of using Q methodology for the two example studies (Mengesha et al. 2017; Dune et al. 2017).

6 Conclusion and Future Directions

This chapter provides readers with an introduction to Q methodology, a mixed methods approach to exploring phenomena using quantitative and qualitative principles within an interdependent data collection, analysis, and interpretive strategy. This chapter outlined the five steps involved in conducting a Q methodology study (i.e., (1) developing the concourse, (2) developing the Q set, (3) selection of the P set, (4) Q sorting, and (5) Q analysis and interpretation). Examples from our own work with Q methodology across a range of fields, including constructions of sexual and reproductive health, chronic low back pain, and culturally and linguistically diverse people, demonstrate the breadth and potential applicability of Q methodology to many other fields of study. Q methodology presents as a means for engaging participants in the development of data collection tools and a way to better understand those perspectives from a range of subjective viewpoints.

Q methodology presents many strengths, as it provides a multidimensional perspective on human experiences and engages users both directly and indirectly in the process of inquiry. For the researchers, the steps are easy to follow, although sometimes time intensive. Reducing the logistical requirements for time is supported by software which assists with data collection and analysis so

Table 2 Pros and cons of Q methodology for the example studies

Example studies	Pros	Cons
Challenges in the provision of SRH care study (Mengesha et al. 2017)	Q methodology has demonstrated suitable to generate diverse accounts of a cross-cultural nature that are difficult to capture using other pattern analysis approaches	Sorting using Q- Assessor has been confusing for some participants
	The use of Q-Assessor has simplified data collection, analysis, and interpretation stages	Time-consuming (inception to publication ~ 2 years)
	Allows researchers to compare the subjective viewpoints of the HCPs and the extracted factors	Generalizations could not be made due to the gender and age composition of the participants
	The purposeful nature of the sampling strategy helped to achieve a comprehensive sample that ensured the perspectives identified reflected the experiences of providing SRH care to refugee and migrant women in a broad sense	
Constructions of SRH from the perspective of 1.5 generation migrant study (Dune et al. 2017)	The ability to explore perspectives in relation to individuals (vs the other way around)	Generalizations cannot be made as the sample was limited to 42 migrants who lived in metropolitan Sydney and near university campuses
	Apply principles of quantitative variance to concepts derived from subjective viewpoints	Requires some upskilling and some mentorship to adequately complete a Q study
	Clarity around variables that are impactful yet not accounted for in the Q set provides clear avenues for further research	
	A research strategy that is multidimensional and easy to do provided adequate mentorship is provided	
	Larger sample compared to other traditional qualitative research methods	Forced choice might have slightly influenced the findings
	Results from Q methodology could be triangulated with other research methods, such as open-ended questions and validated questionnaires	Some participants may have experienced difficulties in understanding the process of completing the study

(continued)

Table 2 (continued)

Example studies	Pros	Cons
	Participants could participate from home using Q-Assessor	Findings cannot be generalizable and require further research to understand whether reducing stress can help to better cope with chronic low back pain (LBP)
	Participation was not time-consuming (around 40 min)	
	Findings provided new insights for i) clinical practice on the importance to screen and then intervene to reduce stress in people with chronic LBP; ii) further research to find the most effective strategies and interventions for stress management	

that interpretation can be expedited. As with most software, the price for such a service can be prohibitive to some researchers especially students, early career researchers, independent researchers, or smaller organizations with limited research capacity. While there is a range of software available for free or at a minimal cost, time is required to ensure that the researcher is well versed in using the software and procedures for accurate input and analysis of the data. Given that Q methodology is research strategy being rediscovered by researchers across a range of fields outside of psychology and marketing, it is likely that software packages will continue to develop and become more affordable. In doing so, more researchers can gain information, access, and engagement with this innovative research strategy.

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Social Network Research

44

Janet C. Long and Simon Bishop

Contents

1	Introduction	770
2	Network Analysis in the Social Sciences: A Brief History	771
3	Social Network Concepts	771
4	Structure Versus Agency	772
5	Methods	774
6	Key Players in Collaborative Networks	775
7	Social Network Analysis and Healthcare Research	776
8	Conclusion and Future Directions	780
	References	780

Abstract

Analysis of networks is increasingly seen as important for understanding the patterns, processes, and consequences of social relationships in healthcare. Networks can be formal, mandated structures (e.g., a clinical network), can emerge from sharing a common passion, or can be from routine exchanges such as referrals. Braithwaite and colleagues (2009) call for the fostering of naturally emerging networks suggesting these underpin the delivery of healthcare and play an important role in driving quality and safety. Social network analysis (SNA) emphasizes patterns of relationships and interactions between network members (actors) rather than individual attributes/behaviors or abstract social structures. SNA conceptualizes networks as composed of nodes (the actors in the group) and

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769

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ties (the relationship between the actors). Ties form the structure of the network, and the nodes occupy positions within that structure. This proves a basis to investigate a wide range of issues, including communication pathways between actors (including gaps, bottlenecks, or opportunities to increase connectivity), the presence of “tribes” or silos, key players, networks of social support, and patterns of social influences on behaviors. This also allows researchers to investigate relationships between network structures (e.g., communication flows) and important outcomes (e.g., rapid dissemination of ideas). In this chapter, we will introduce readers to key debates, concepts, methods, and applications of SNA, drawing on the authors’ own studies and the growing body of healthcare literature adopting this approach. This demonstrates the contribution of SNA to understanding different types of networks, including at the individual, group, and organizational level.

Keywords

Interprofessional relationships · Collaboration · Connectivity · Brokerage · Knowledge exchange

1 Introduction

Analysis of networks is increasingly seen as important for understanding the patterns, processes, and consequences of collaborative relationships in healthcare. Networks can give a more holistic picture of the complex interactions which define the health system. Networks can be formal, mandated structures (e.g., a clinical network Haines et al. 2012), can emerge from sharing a common passion (e.g., a special interest group or community of practice Wenger et al. 2002), or can be from routine exchanges (e.g., referrals Fuller et al. 2007). Braithwaite et al. (2009) call for the fostering of naturally emerging, bottom-up networks, suggesting these underpin the delivery of healthcare and play an important role in driving quality and safety.

A network is any group of people or objects that can be said to interact or have some kind of relationship between them. Network theory provides a powerful lens through which to understand how the elements within such a group are organized, following a set of principles. The study of networks led to the realization that there are similarities between very diverse types of networks such as the neural networks of nematodes (Morita et al. 2001), power grids (Nasiruzzaman 2013), and the Internet (Carmi et al. 2007). In the social sciences, network theory is used to explain interpersonal relationships at various scales: from whole of communities (Putnam 1995) to a few clinicians exchanging information about a patient (Benham-Hutchins and Effken 2010). It provides insight into such phenomena as the influence of opinion leaders, why some companies have a competitive edge, and how effective teams work.

This chapter starts with a brief history of social network studies, followed by an introduction to basic network concepts and methods. We then describe studies which have used social network methodology to study aspects of health service delivery.

2 Network Analysis in the Social Sciences: A Brief History

The study of patterns of social relationships has been an enduring aspect of social science (Durkheim 1895; Simmel 1950). Here, we focus on social network analysis (SNA) as a distinct methodology, emerging in the mid-1930s in the social and behavioral sciences and advancing slowly but constantly over the next 60 years by a small core of researchers at Harvard. As Wasserman et al. (2005, p. 1) put it: “It was easy to trace the evolution of network theories and ideas from professors to student, from one generation to the next.”

The psychiatrist, Jacob Levy Moreno (1889–1974), is often cited as the father of network analysis although Freeman (1989) argues that the structure of networks was recognized long before this in the kinship structures such as descendant lists in the Old Testament (e.g., Genesis 5). The first use of the term “network” as it is understood today (Freeman 2004, p.35) was in Moreno’s seminal study on Hudson School for Girls and Sing-Sing Prison (Moreno and Jennings 1934). Moreno stated that the schoolgirls’ action of running away was influenced more by their position within their social network than with a conscious, independent decision. Moreno used the term “sociometry” to describe “the mathematical study of psychological properties of populations . . . methods which inquire into the evolution and organisation of groups and the position of individuals within them” (p.10). In other words, it is a method for eliciting and mapping the subjective feelings of individuals toward each other (Borgatti et al. 2009), focusing analytic attention on patterns of social relationships.

During the 1940s and 1950s, social network research developed through matrix algebra and graph theory, allowing the groups to be objectively identified within networks (Luce and Perry 1949). This led to work exploring concepts such as leadership, group cohesiveness, group productivity, cooperation, competition, communication and problem solving, and the spread of influence within groups (Borgatti et al. 2009; Freeman 2004). Around 1990, there was a massive rise of interest in networks, as other disciplines outside of sociology saw their potential, disciplines as diverse as physics and epidemiology (Wasserman and Faust 1994). A major contribution to network analysis was the characterization and modeling of small-world networks (Travers and Milgram 1969; Watts and Strogatz 1998). Small-world networks have been found in many settings including brain networks (Zhang et al. 2016) and food webs (Montoya and Solé 2002). Small-world networks display properties that transcend the characteristics of the individuals within it.

3 Social Network Concepts

SNA emphasizes patterns of relationships and interactions between network members (actors) rather than individual attributes. Actors can be individuals or entities such as departments or whole organizations, while relationships, which must be tightly defined, can be things such as collaboration, friendship, information exchange, or attendance at a particular event. While attribute data (e.g., gender,

age, job position, seniority) is usually also collected, the focus is on this relational data that defines the network structure (Scott 2000). Different types of relational tie can lead to very different network structures; for example, a network of friendship ties between actors may be different from the same actors' network of reporting ties.

Ties can be directional (e.g., providing information to, seeking advice from) or nondirectional (e.g., works in the same building, attend the same meeting). Ties can be recorded as simply present or absent or weighted to signify the weakness or strength of a relationship. This can be based on emotional intensity, level of reciprocity, or more usually frequency of contact (Granovetter 1973).

Relational tie data can be collected in different ways depending on the nature of the interaction. Face-to-face communication patterns may be directly observed (e.g., Obstfeld 2005). Referral patterns, email communications, or collaboration may be gathered using a self-report survey (Bishop and Waring 2012; Chan et al. 2016; Long et al. 2016) or documentary evidence (Fattore et al. 2009; Zheng et al. 2010).

SNA conceptualizes networks as composed of nodes (the actors in the group) and ties (the relationship between the actors) to generate sociograms. The ties form the structure of the network, and the nodes occupy positions within that structure. This proves a basis to investigate a wide range of issues, including communication pathways between actors (including gaps, bottlenecks, or opportunities to increase connectivity), the presence of "tribes" or silos, identification of key players, defining networks of social support, and revealing patterns of social influences on behavior. This also allows researchers to investigate relationships between network structures (e.g., communication flows) and important outcomes (e.g., rapid dissemination of ideas). Table 1 summarises key terms in social network analysis.

Social network theory has been used to understand processes and phenomena across a range of different industries and settings including market competition (Burt 1992; Uzzi 1997), generation of innovative ideas (Bercovitz and Feldman 2011; Hargadon and Sutton 1997), influence and leadership (Lambright et al. 2010; Long et al. 2013b; Valente and Pumpuang 2007), and group dynamics (Balkundi et al. 2009; Susskind et al. 2011).

Within healthcare, social network theory and analysis have been used to look at coordination and integration of health services (e.g., Ayyalasomayajula et al. 2011; Khosla et al. 2016; Lower et al. 2010; Ryan et al. 2013), interprofessional communication and practice (e.g., Benham-Hutchins and Effken 2010; Chan et al. 2016; Creswick et al. 2009), strategies for translational research (e.g., Long et al. 2016; Rycroft-Malone et al. 2011), influence and leadership (e.g., Grimshaw et al. 2006; Kravitz et al. 2003), and quality and safety (e.g., Cunningham et al. 2012; Meltzer et al. 2010).

4 Structure Versus Agency

A debate within SNA research is the difference between two conceptualizations, usually referred to as structure and agency to explain human behavior and social networks. A structuralist view focuses on the recurring patterns of social interactions

Table 1 Some social network terms and their definitions

Term	Definition
Actor	A member of a network
Broker	An actor in a network that acts as an intermediary between two unlinked actors and clusters of actors
Brokerage	A strategy described by Burt (2005) of maximizing opportunities by increasing variation in the network through weak, bridging links to multiple, nonredundant contacts outside the group. This strategy contrasts with closure
Central actor	The actor who is nominated most often or who interacts with the most other members of a network
Centrality	A measure of which actor or actors are the most connected or who interact with the most other actors
Closure	A strategy described by Burt (2005) of increasing cohesion by reducing variation within a group by forming strong links to members of the network. This strategy contrasts with brokerage
Cluster	A subgroup of a network in which the local density of ties is higher than across the whole network
Contagion	The process of spreading disease (in epidemiology), ideas, knowledge, or uptake of new technology through direct contact or social influence in social networks
Degree	The number of ties that actors have to other actors
Density	The ratio of the number of ties present in a network divided by the number of possible ties
Directed tie	A tie that contains information about who initiated the tie and who receives it (e.g., information given by Actor A and received by Actor B)
Node	Element of interest in a network. In a social network, it may be an individual or organization. In nonsocial networks, it may be an object, e.g., a station in a railway network
Edge (or tie)	A link or relationship between actors in a network shown on sociograms as a line
Ego	Focal actor in a network
Egonet	Social network of a single focal actor
Homophily	Defined by Rogers (2003) as the extent to which linked actors share similar attributes such as education, gender, or social status
Reciprocity	A tie is said to be reciprocated when both actors acknowledge the tie
Social capital	A measure of the advantage that comes through social ties. May refer to the advantage held by an individual through their egonet (Burt 1992) or may refer to the quality of an entire group, e.g., an entire community (Putnam 1995)
Strength of tie	A measure of emotional intensity, level of reciprocity, or frequency of interaction associated with a tie
Strength of weak ties	A phenomenon described by Granovetter (1973) to describe the often advantageous, novel information that comes from weak links from outside of one's closely tied network (who all tend to know the same information)
Tie (or edge)	A link or relationship between actors in a network shown on sociograms as a line
Undirected tie	A tie that does not require information about who initiated the tie or who received it (e.g., two actors on the same board, kinship ties)
Whole network survey	A survey that aims to elicit data from every member of the network, rather than a sample of members

that appear to provide opportunities to an individual or constrain their behavior (Ansell et al. 2009). Agency, on the other hand, refers to an individual's power to act and purposefully change their world (Apelrouth and Edles 2008).

A structuralist perspective of networks takes the view that a certain individual's position in a network influences their actions (and consequences) as network positions afford certain opportunities. An actor in a central position in a network might be expected to have the same opportunities and constraints as another central actor in a different network. This approach focuses on the presence or absence of ties and tends to ignore the actual content of the ties ("ties conceptualised as girders" (Borgatti and Foster 2003, p.1003)). An example of this approach is a study of hospital facility managers (Heng et al. 2005) in which they illustrated through a sociogram that managers were situated centrally in the overall network between departments. This meant that they were able to act as coordinators and brokers between the many departments with which they linked.

An agency perspective perceives the actor taking a greater role and using the resources of the network to his or her own end. Agency-focused studies of networks try to understand how the individual's actions and behavior have shaped their environment. This approach focuses on the nature of the ties, more specifically, on the resources that are delivered in the ties ("ties conceptualised as pipes" Borgatti and Foster 2003, p.1003). A small study by Kalish (2008) considered the personality traits of students in brokerage positions in a multicultural class to understand the nature of personal agency in defining their network position.

Networks are not static structures, so some studies have used both agency and structural perspectives in the same study. For example, Johnson et al. (2003) described the relationships between crew members at an Antarctic science base over three successive winters. As well as network structural data ("who hung out with who"), they observed the social roles that people took within the networks ("clown," "leader who got things done"). By combining the data, they were able to describe the emergence and evolution of the network. Both viewpoints have merit and are inherently interesting to explore. Borgatti and Foster (2003), in their review of network research, however note that the vast majority of SNA studies take a structuralist perspective.

5 Methods

Social network data can be collected through self-report surveys, observation, or use of documentary data (e.g., emails, minutes of meetings). Before starting to collect data, the most important step is to define the relationship of interest. Referral or specific advice relationships may be straightforward, but for self-report surveys especially, the tie needs to be understood in the same way by all participants. Long et al. (2016), for example, used the following explanation of collaborative ties since collaboration is a multifaceted concept that had the potential to be understood in a number of different ways: "By 'collaboration' we mean either formally (e.g., on a funded project) or informally (e.g., have discussed aspects of research, supplied

expertise, advice or equipment to others) ... Please select those people with whom you are currently collaborating on a network activity, event or project ...” (p. 6). This allowed the researchers to capture informal collaborative ties as well as the formal.

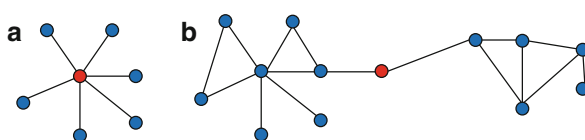
Two main methods of eliciting relationship data in the self-report survey method are roster style and name generator. If the boundaries of the network are known (e.g., people signed up to an online community of practice, staff on a ward, members of a committee), a roster of names may be used (pending ethical and governance approval). In the roster style survey, the members of the network are listed, and the respondent is asked to consider each person as a potential tie. In the name generator style of survey, the respondent is asked to write down the names of the people with whom they consider they have the defined tie without any prompting. This is useful if the membership of the network is not known (e.g., social support networks). The following resources provide detailed discussion of SNA methods and the various advantages and limitations associated with them (Borgatti et al. 2013; Scott 2000; Wasserman and Faust 1994).

6 Key Players in Collaborative Networks

Highly influential actors can be identified within networks, defined by their position in the overall structure. These actors are often called key players (Borgatti 2006), but there are a range of terms used in literature to describe them. Highly connected actors that occupy central positions in the network are termed opinion leaders (Gifford et al. 1999; Valente 2006; Valente and Pumpuang 2007), hubs (Buchanan 2003; Watts and Strogatz 1998), or connectors (Gladwell 2000 p.38). Moreno used the term communication “stars,” referring to actors who are chosen as friends by the most people (Moreno and Jennings 1934 p.72), and Allen used this to refer to actors who are approached most often for advice in a work setting (Allen 1970). Central actors appear to sit at the center of a star when ties are graphed (see Fig. 1a).

Brokers are actors that link together individuals or groups of individuals (see Fig. 1b). They have been identified using a range of terms, the most common being bridges (Burt 1992; Valente and Fujimoto 2010), brokers (Cross and Prusak 2002; Gould and Fernandez 1989; Shi et al. 2009), and boundary spanners (Howse 2005; Tushman 1977). The broker is considered a key player as their position is inherently powerful; they may be the sole link between two noncommunicating groups. This can be used for a competitive advantage in business (e.g., having information from group A that group B does not, means the broker has a competitive edge) or to cause

Fig. 1 (a) Star-shaped graph: the central actor is colored red. (b) Broker (in red) bridges two separate clusters of actors



mischievous (e.g., hoarding relevant information and not passing it along; acting as a gatekeeper and not allowing access to resources held by the other group). More positively, in collaborative networks, they can broker beneficial introductions, mediate between parties that are at odds, or provide a service of some kind to both parties (e.g., an interpreter, an expert).

Both key player roles have costs associated with them as well as advantages (Long et al. 2013c). Maintaining ties is a time-consuming exercise and beyond a certain number is unfeasible (Burt 1992, 2002).

7 Social Network Analysis and Healthcare Research

Social network analysis is a powerful approach to apply to healthcare settings. It can provide a framework to examine information flows, social and professional influence, and the phenomenon of siloed thinking and action (Long et al. 2016). While SNA has been well noted for its potential to map epidemiological phenomenon (e.g., the spread of HIV (Lin et al. 2012) or SARs (Chen et al. 2011)), over the past 10 years, it has also been increasingly taken up in research on healthcare organizations and systems. A number of reasons for this interest can be suggested. The increasing focus on the shape of social networks can be seen to follow from a concern with network forms of governance and policy attempts to engage with, and harness, embedded professional networks. Rather than an integrated hierarchy, it has increasingly been recognized that multiple “decentered” professional and organizational networks are involved in shaping and controlling health systems; SNA offers an approach to study such network forms.

A related concern of healthcare researchers is the nature of relationships between heterogeneous professional and occupational groups, how work is divided, and the implications for the coordination of care and fostering of collaboration. Rather than focusing on the aggregate relations, as has been common in perspectives such as sociology of the professions, SNA allow empirical investigation of patterns of relationships at the individual and subgroup level.

Third, an increasing concern of healthcare researchers over the past 15 years has been how knowledge, particularly new knowledge from research evidence and innovation, is translated and diffused into practice. SNA has also been used to examine the strategy of using translational research networks to bridge the “valley of death” (Butler 2008) between basic science and bedside, “real-life” practice. Again, SNA has shed light the patterns of relationships that underpin this process and how knowledge translation and improvement efforts can be supported. Two examples of author projects demonstrate recent applications.

Example 1 SNA of translational research strategies

Translational research undertakes the crucial role of moving biomedical discoveries out of the highly controlled laboratory environment and applying it in the complexity of patient and service delivery realities (Goldblatt and Lee 2010; Woolf 2008). Expertise and understanding through collaboration between both fields are necessary

to achieve this, yet the gaps between research and clinical domains are widening through increased specialization and complexity (Schwartz and Vilquin 2003; Zerhouni 2005). Translational research networks are a strategy to facilitate collaboration by establishing a clear, joint vision and setting up an administrative structure to provide funding for joint projects, project officers, and shared resources as well as a social structure to maximize opportunities for collaboration, innovation, and knowledge exchange. While potential partners in such networks may abound, clusters within disciplines, professions, or geographic sites and the gaps between them may hinder their initiation. This study used SNA at baseline and three further points in time to examine changes in collaborative ties between members with reference to these clusters (Long et al. 2012, 2013a, b, 2014, 2016).

The translational research network of interest was established in late 2011, and initial membership was 68 cancer clinicians and researchers drawn from 6 hospital and university sites in New South Wales. An online, whole network survey was administered to all registered members of the network in early 2012, in 2013, and again in 2015. Membership changed in that time from 68 to 263 to 244 (respectively) as people joined or left. SNA showed that at baseline, ties of the original members were reflective of long-standing teaching and research arrangements and clustered by field (clinician or researcher) and by geographic proximity. Over the next 4 years, collaborative ties were shown to be bridging the field gap and including consumers in both research- and clinically based projects, although geographic proximity remained a feature. Key player analysis showed that the network manager was enacting a significant brokerage role in bringing new collaborative partners together, a quantitative finding that was confirmed through interviews (Long et al. 2013b).

In a similar project (unpublished Long and McDermott 2017), SNA was used to examine the growth of collaborative ties within a translational research network in the field of dementia. The network was shown, by the second year of operation, to have successfully brokered collaborations across formerly siloed sectors of academia, industry (largely staff in residential care facilities), consumers (people living with dementia and representatives from consumer advocacy groups), and government (policy-makers, regulators, and accreditation purveyors). Sociograms from the first survey at baseline (Fig. 2) and after 2 years of operation (Fig. 3) show this growth of intersectoral collaboration. External/internal (E/I) index analyses at the two points in time showed that at baseline, members from each sector were more likely to collaborate with people within their sector than with people in another sector, while after 2 years, members were more likely to collaborate with members outside their sector. In the last survey, there were 857 new ties ($n = 121$) described as “I have only worked with this person since joining the network.” Again, key player analysis showed both the centrality of the network manager and director and their brokerage roles.

Example 2 Mixed methods SNA: relations between health and social care

The second example focuses on a study of knowledge sharing on issues of patient safety within a UK NHS hospital day surgery department. In light of well-recognized professional silos within health organizations (Waring 2004; Currie et al. 2008), this

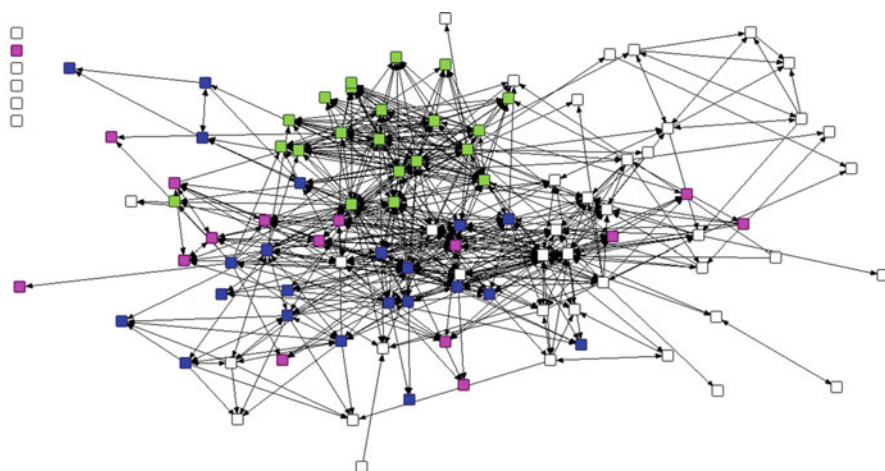


Fig. 2 Baseline collaboration in a dementia translational research network ($n = 104$). The four sectors are shown by color: green = consumers, blue = academics, white = industry, pink = government. Gray nodes indicate missing sector data

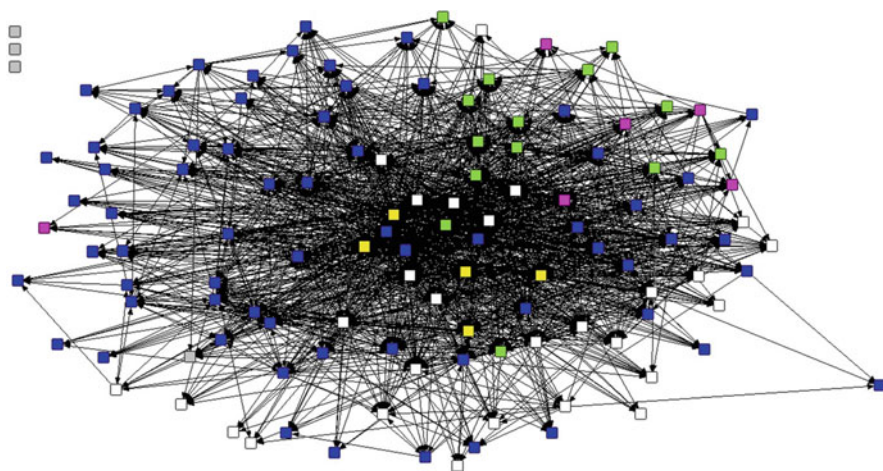


Fig. 3 Collaboration ties after 2 years of operation of a dementia translational research network ($n = 121$). While academics outnumber other sectors, cross-sectoral collaboration was demonstrated quantitatively and is now more evident visually (Legend as for Fig. 2)

study aimed to investigate the patterns of knowledge sharing within and between professional groups. The methodology involved both a quantitative SNA survey and a period of ethnographic observations. The quantitative SNA survey was designed to elicit respondents' close advice-giving contacts, asking respondents to provide named individuals within the department from whom they most commonly sought knowledge around patient safety, as well as the frequency of advice. Demographic

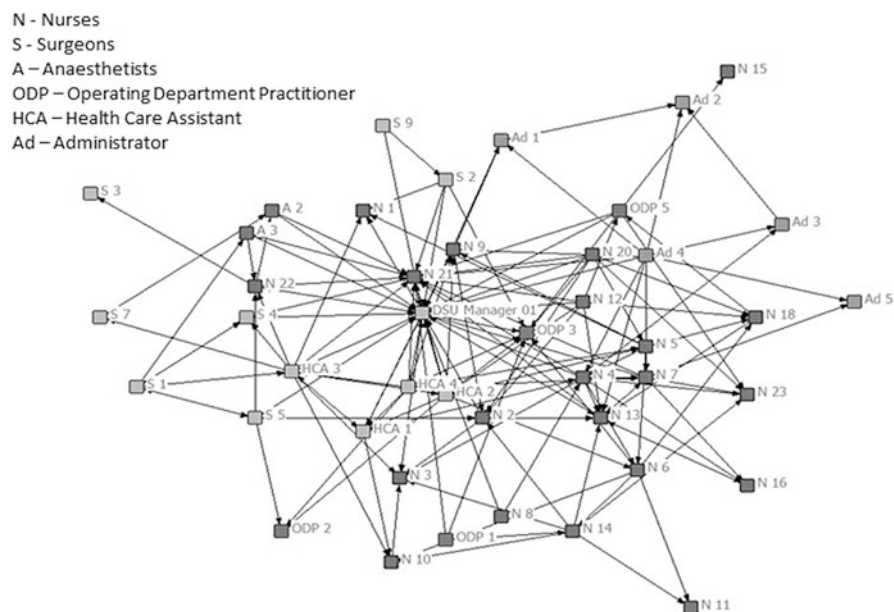


Fig. 4 Network of advice-seeking ties within a UK NHS hospital day surgery department

data was also collected on the professional background, tenure, and work role of the respondent. Full network data was sought from all members of the department, identified both through an initial staff list and through following up new individuals identified in the name generator of respondents ($n = 47$, 85% response rate). Alongside this, 250 hours of ethnographic observations were undertaken, focusing on working practices and communication across settings within the department, as well as 40 qualitative interviews (see Bishop and Waring 2012).

Results from the study brought to light a number of key issues surrounding knowledge sharing within the department (see Fig. 4). Quantitative SNA results illustrated the complex web of intra- and interprofessional knowledge-sharing relationships in the department and highlighted (1) medics' position toward the periphery of the network, (2) the central role of senior nurses in the advice network of the department, (3) the peripheral role of part time and temporary staff, and (4) that a higher number of advice-seeking ties were held within professional groups than between groups. These findings supported prior theorizing in relation to trust and knowledge sharing within professional groups (Chan et al. 2016; Creswick et al. 2009). They also appeared to reflect aspects of service organization, for example, the central administrative role played by senior nurses within the department and medics attached to external departments of their clinical specialisms.

Alongside the quantitative SNA findings, the qualitative component of the study allowed further exploration of the patterns of advice giving within the quantitative

SNA and provided insight into the meaning of the identified relationships. This work included examination of how work practice shaped the opportunities for interaction and hence knowledge sharing within and between groups. It also explored important factors shaping how individuals sought to negotiate relationships within the department while responding to conflicting demands. Bringing together quantitative SNA and qualitative research methods could, therefore, help to develop both an understanding of the structure of social relationship and the way these relationships are formed and maintained within the everyday practice of health organizations.

8 Conclusion and Future Directions

Researchers of health systems are increasingly recognizing that the socio-professional relationships are an essential component of quality, safety, and efficient delivery of care. SNA is a valuable tool to quantify these relationships at both an individual and organizational level. Patterns of collaboration, referral, and knowledge exchange are revealed by SNA and in combination with complementary qualitative methods such as ethnographic observation or interviews, fleshed out to give insight into social processes in healthcare. In addition, SNA is an important methodology for understanding emergent networks which have been shown to drive safety initiatives (Braithwaite et al. 2009).

SNA is an important methodology to analyze new social structures to drive policy and reform, cross-sectoral collaboration, integration of services, and dissemination of best practice. The use of SNA to reveal the utility of translational research networks as a strategy to create a common vision and broker-bridging relationships has been shown. SNA is also an important methodology for examining managed network structures as mechanisms of policy and reform. As public policy emphasizes dispersed leadership and accountability within networks, an understanding of the strength of relationships and how network roles such as brokerage are enacted is important. Further theory around network development and durability of relationships is another avenue for future research.

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Meta-synthesis of Qualitative Research

45

Angela J. Dawson

Contents

1	Introduction	786
2	Meta-synthesis: A Historical Overview	787
3	Approaches to the Meta-synthesis of Qualitative Data	788
3.1	Purpose	788
3.2	Position	789
3.3	Paradigm	790
4	Practical Approaches to Undertaking a Meta-synthesis	793
4.1	Defining the Scope of the Study	793
4.2	Question Design	793
4.3	Developing an Inclusion Criterion and Forming Keywords	795
4.4	Selecting a Method or Approach to the Synthesis of Qualitative Data	796
4.5	Developing a Protocol	797
4.6	Technology to Support Meta-synthesis	797
4.7	Searching and Selecting/Sampling Studies	798
4.8	Appraising Qualitative Studies in the Review	798
4.9	Extraction and Synthesis Processes	799
5	Conclusion and Future Directions	800
	References	802

Abstract

A meta-synthesis of qualitative health research is a structured approach to analyzing primary data across the findings sections of published peer-reviewed papers reporting qualitative research. A meta-synthesis of qualitative research provides evidence for health care and service decision-making to inform improvements in both policy and practice. This chapter will provide an outline

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785

of the purpose of the meta-synthesis of qualitative health research, a historical overview, and insights into the value of knowledge generated from this approach. Reflective activities and references to examples from the literature will enable readers to:

- Summarize methodological approaches that can be applied to the analysis of qualitative research.
- Define the scope of and review question for a meta-synthesis of qualitative research.
- Undertake a systematic literature search using standard tools and frameworks.
- Examine critical appraisal tools for assessing the quality of research papers.

Keywords

Meta-synthesis · Qualitative research synthesis · Systematic review · Meta-ethnography · Meta-summary · Narrative synthesis

1 Introduction

A meta-synthesis of qualitative health research is a structured approach to analyzing primary data across the findings sections of published peer-reviewed papers reporting qualitative research. The analysis of this evidence involves qualitative and sometime quantitative methods with the aim of improving health outcomes, research, services, or policy. Meta-synthesis involves a process that enables researchers to examine a phenomenon such as health-care experiences or understandings of health or well-being, as well as environmental, organizational, and individual factors that affect the implementation or effectiveness of a health-care service or clinical intervention and the complex interaction of these. The approach involves searching for, selecting, appraising, summarizing, and combining qualitative evidence to answer a specific research question. A meta-synthesis of qualitative evidence involves interpreting the interpretations made by the authors of the studies included in the meta-synthesis to provide insights for practice or policy. These insights are theoretical and involve methodological development combined with critical reflexivity, thereby adding to, refining, and extending the meaning of original qualitative studies.

Meta-synthesis, therefore, involves the study of the underlying assumptions of various qualitative findings in the included studies, comparing different types of data according to their quality and utility and synthesizing and interpreting the findings of research studies that relate to the same phenomenon. The approach has been described as “the bringing together and breaking down of findings, examining them, discovering the essential features, and, in some way, combining phenomena into a transformed whole” (Schreiber et al. 1997). This approach differs from other qualitative reviews of literature including the integrative literature review both in the explicit, systematic, and replicable steps taken to searching for, screening, and identifying literature and in the approach to the analysis of data contained within the findings of the included research papers. The approach taken to the analysis is

empirical rather than a discursive critique of academic discourse that involves a study of studies rather than an overt examination of their findings (Thorne et al. 2004, p. 1360).

2 Meta-synthesis: A Historical Overview

There is increasing recognition of the important role qualitative research can play in medical research. The movement toward patient-centered care has stimulated much of this recognition alongside public skepticism of medical expertise and scientific knowledge and the change in understanding the patient as a client and consumer of health care. While this has done much to raise the voices of patients/clients/consumers in decisions concerning health care and engage communities in the co-production of health services, there has been an acknowledgment of the important role of attitudes and beliefs in health-related behaviors and beyond the social determinants of health. This understanding has recognized that to improve health, an examination of sociocultural values is needed that necessitates qualitative data and research methods. Despite many researchers rejecting the British Medical Journal's suggestion that qualitative research, lacking in conclusive findings or clinical implications, should be published in specialist journals (Greenhalgh et al. 2016), there is a growing acknowledgment that experimental designs are not suited to answering many health research questions (see also ► Chap. 7, "Social Constructionism").

In addition to these developments, there has been an increasing focus on systematic reviews to support evidence-based health care including reviews of qualitative studies and qualitative approaches to reviewing qualitative and quantitative research. This change is visible in the actions of the Cochrane Library whose traditional statistical methodological expertise in meta-analyses has expanded to incorporate qualitative evidence in syntheses. In 2006, the Cochrane Qualitative and Implementation Methods Group (CQIMG) was established, and the latest guidance on qualitative reviews is now included in the Cochrane Handbook (Noyes et al. 2015). The meta-syntheses of qualitative studies have an important role to play in health-care decision-making by either augmenting quantitative meta-analysis through investigative questions linked to effectiveness or complementing meta-analysis to address questions on aspects other than effectiveness. In addition, meta-synthesis of qualitative evidence can help to frame research questions and identify gaps where further qualitative and quantitative research and/or systematic reviews should be undertaken. The CQIMG has recently published guidance on methods for integrating qualitative and implementation evidence within intervention effectiveness reviews (Harden et al. 2017). The group published a paper to illustrate how qualitative evidence can be used to compliment quantitative evidence to provide a more nuanced understanding of service delivery in the case of tuberculosis (Noyes and Popay 2007). However, it was not until 2013 for the first review of qualitative evidence to be published in the Cochrane Library (Glenton et al. 2013).

The meta-synthesis of qualitative research has its roots in the social sciences and early efforts such as those by Noblit and Hare who developed a procedure in the 1980s to work out “how to ‘pull together’ written interpretative accounts” (1988, p. 7). An increased trend in the number of published meta-synthesis of qualitative evidence has been noted (Hannes and Macaitis 2012; Tong et al. 2012), indicating a growing interest in the field and rapid development and refinement of approaches and methods.

3 Approaches to the Meta-synthesis of Qualitative Data

There are approximately 20 methods to synthesize qualitative evidence (Hannes and Lockwood 2012, p. 5). This variation in review methods highlights the nature of the evolving field of meta-synthesis but also the different understandings of knowledge, worldviews, and aims of researchers. This involves the researchers articulating the purpose of their review, the epistemological position, and the paradigm aligned with the choice of methodology.

3.1 Purpose

Researchers have set out to achieve several objectives in their meta-synthesis of qualitative research that represent a range of motivations that can be understood across a continuum (see Fig. 1). Those wishing to deliver practical insights for health policy and practice decision-making are more likely to adopt an approach that is highly structured and involves systematic sampling of research reports and use an a priori conceptual framework derived from the literature to help direct and define the study and triangulate the findings. The approach to the analysis of data will, therefore, involve summation, enumeration, or aggregation in a directed or deductive

Purpose		
Utilitarian/ practical		Theoretical
Test	Explore	Generate
Examine apriori values		conceive values a posteriori
Aggregate		Interpret
Reason deductively		Reason inductively
Generalizability of findings		Transferability of findings
Context specific insights		Multi-context insights
Synthesize quantitative or quantitative and qualitative evidence		Synthesize qualitative evidence

Fig. 1 A continuum of purposes dictating the approach to the synthesis of data

manner. Quantitative approaches to the analysis of qualitative evidence could be used for this purpose such as Bayesian methods for synthesis. This can involve converting qualitative data into numerical data so that it can be used together with quantitative data to calculate the likelihood of a hypothesis being invalid. For example, in Voils et al.' study (2009), qualitative data is quantified and analyzed to test if decreased adherence to antiretroviral medication would be associated with more complex drug regimes. The purpose is to draw conclusions that could be applied or generalized across different populations. This approach is aligned with a meta-analysis rather than a meta-synthesis as the focus is on statistical methods to improve estimates of the size of the effect of a given intervention.

Structured approaches employed to synthesize both qualitative and quantitative evidence from research reports that do not employ inferential statistical methods include narrative synthesis and critical interpretive synthesis. If the purpose is to synthesize qualitative evidence only, then a qualitative meta-summary (Martsolf et al. 2010) or ecological triangulation (Banning 2005) may be better suited. These approaches are more exploratory and less on the testing extreme of the continuum.

On the other hand, researchers may be aiming to generate theory such as in the case of Walder and Molineux (2017) who sought to develop a framework to understand occupational adaptation and identity for those affected by chronic disease and serious illness. The authors did not employ a priori organizing categories for data analysis. The context of the data is particularly valuable in this analysis to provide insight into how the framework can be applied to understand the experiences, perceptions, and needs of other populations.

While researchers may conduct a review with a particular selection of studies to gain insight into one specific context to provide targeted insights, reviews involving multiple contexts will require detailed information about cultural and organizational factors so that this can be considered for relevancy (Hannes and Harden 2011). This highlights the importance of a research team that is diverse in culture, age, gender, and disciplines so that new theoretical insights can be jointly created to address and explore a common issue.

3.2 Position

As meta-synthesis is an interpretive syntheses of qualitative data, it involves drawing upon methodological insights from phenomenology, ethnography, grounded theory, and other theories to integrate and make comprehensible descriptions or accounts of phenomena, cases, or events (Sandelowski and Barroso 2006). The choice of methodology, therefore, depends upon the question, the understanding of knowledge, and study lens or theoretical perspective. This involves adopting an epistemological position that underpins the approach to the review (see also ► Chap. 6, "Ontology and Epistemology"). Barnett-Page and Thomas (2007) have described approaches to the synthesis of qualitative research along epistemological dimensions where, at one end, there is subjective idealism, a theory that espouses that knowledge cannot be known and that truth is subjective. As such, there can be no shared reality

Position			
Realist		Idealist	
Objectivist	Constructivist		Subjectivist

Fig. 2 Epistemological dimensions

that is independent from the many human constructions of knowledge. At the other end of this epistemological dimension is naïve realism where knowledge can be known but exists independently from human construction as objective truth. Crotty (1998) has described qualitative research across three epistemological positions: objectivist where meaning and reality exist separate from human consciousness; constructivist, where meaning originates from our interactions with the world; and subjectivist, where meaning is imposed on an object by a human (see Fig. 2).

At the scientific realist, objective end of the dimension, the review by Seymour et al. (2010) is focused on delivering robust findings for health-care decision-making that involves defining a clear question that remains constant throughout the study and a structured process of analysis (framework analysis) and interpretation to answer the review question. Here, knowledge is understood as representing an external reality that can be extracted and used to improve health professional communication with family members following genetic testing for cancer risk. An example of a review positioned toward the idealist constructivist end of the dimension is a review by Franzen et al. (2017) that employed a meta-narrative methodology to explore different approaches to health research capacity development in low- and middle-income countries over time. In this study, all approaches are different and alternative ways of understanding capacity building, and as such, the authors embrace heterogeneous evidence from multiple contexts.

3.3 Paradigm

The epistemological position and the methodological premise of a meta-analysis can be understood according to the paradigm it is aligned with (see Fig. 3). The associated paradigm provides a set of guiding principles that dictates how researchers approach the study of phenomena and how the results can be interpreted. This “set of beliefs” (Guba 1990, p. 17) includes post-positivism, constructivist/interpretive, critical theory, subjectivism, and pragmatism (Denzin and Lincoln 2011). These paradigms, however, are not discrete categories, but rather a continuum of theoretical assumptions underpinning reviews that are not always clear cut (Gough et al. 2012).

While post-positivists agree that reality can be measured, observation is imperfect, and as a result errors are common, and, therefore, theory is revisable. Bayesian meta-analysis involving the quantification of qualitative data to determine variables and calculate effect sizes (Crandell et al. 2011) is aligned with a post-positivist paradigm. Realist qualitative meta-synthesis reviews approach the study of qualitative evidence (Sager and Andereggen 2012) with this worldview to determine “what

Paradigm dimension	Methodology/approach	Associated theory	Epistemological focus
Post-positivist	Bayesian meta-analysis Bayesian meta-synthesis Meta-summary Realist synthesis Ecological triangulation Case survey Content analysis Narrative synthesis	Logical positivism	Reality can be measured, and the focus is on reliable and valid tools to achieve this
Constructivist/interpretive	Framework synthesis Narrative synthesis Meta-ethnography Meta-narrative Critical interpretative synthesis Meta-study Thematic analysis Formal grounded theory Heuristic inquiry	Symbolic interactionism Hermeneutics Phenomenology Critical inquiry Feminism	Phenomena must be interpreted to discover the many alternate underlying meanings
Critical	Meta-ethnography Grounded theory Discourse analysis Action/ participatory research	Marxism Critical social theory Feminism Queer theory	Knowledge is not neutral, but socially constructed and the product of power relations in society
Subjectivism	Discourse analysis Meta-ethnography	Post-modernism Structuralism Post structuralism	Knowledge and reality is a matter of perspective
Pragmatism	Meta-aggregative, use of multiple methodologies	Deweyan	The focus is on solving the problem or issues using the most appropriate means

Fig. 3 Research paradigms, meta-synthesis methods, theories, and epistemological foci

works for whom and in what circumstances?” (Pawson and Tilley 1997, p. xvi). Qualitative evidence from evaluations of health interventions can be synthesized to determine different context-mechanism-outcome configurations. One example is the examination of community engagement in health programs using qualitative

comparative analysis by Thomas et al. (2014) where theory is refined according to its application to context.

The meta-synthesis of qualitative data involving meta-ethnography, grounded theory, critical interpretive synthesis, and phenomenological analysis are inquiries that can be applied within the constructivist/interpretive paradigm to focus on social processes and the ways in which individuals and communities enact their realities and give them meaning (see also ► Chap. 7, “[Social Constructionism](#)”). Meta-syntheses within a critical theory paradigm include the use of critical or feminist theory to analyze and interpret the qualitative data retrieved from studies in ways that involve a reflective and critical assessment of power relations in culture and society. Authors have suggested that grounded theory may be a useful methodology here (Thorne et al. 2004) where reflexivity can be employed to describe the study purpose and interactions with the data and researchers. Discourse analysis and semiotics may also be used to analyze text in qualitative research synthesis (Onwuegbuzie et al. 2012) to reveal institutionalized patterns of knowledge and power (Elfenbein 2016). Transformative frameworks have been applied in meta-synthesis to generate theory from participatory action or practice to help people address change in the interest of social justice (see ► Chap. 17, “[Community-Based Participatory Action Research](#)”). Oliver et al. (2015) have trialed the use of participatory methods to involve young people in the analysis and interpretation of qualitative data as part of a systematic review to ensure rigor as well as the relevance and feasibility of the findings to reduce childhood obesity. Patients have reported improved confidence and skills as a result of their involvement in such processes (Bayliss et al. 2016). The application of postmodern and poststructuralist methodologies such as deconstruction and genealogical inquiry that are aligned with a paradigm of subjectivism has been little explored in qualitative meta-synthesis.

A pragmatic theoretical perspective underpins a meta-aggregative approach to synthesis to deliver practical and applied insights (Hannes and Lockwood 2011). Value is assigned according to what is useful and the contribution the findings make to the research question. The meta-synthesis is, therefore, the result of questions that have arisen from current situations, needs, and consequent phenomena, not antecedent phenomena (Cherryholmes 1992). Fegran et al. (2014) review of adolescents’ and young adults’ transition experiences when transferring from pediatric to adult care uses multiple methods in line with a pragmatic approach. A meta-summary is used to quantitatively aggregate qualitative findings followed by a phenomenological-hermeneutic analysis. However, other pragmatic decisions may be made in the case of meta-methods where researchers analyze and interpret the interpretations of various methodological applications across many qualitative research studies. Meta-theory involves the analysis and interpretation of different theoretical and philosophical perspectives, sources and assumptions, and contexts across many qualitative studies. This contrasts with a formal grounded theory where the researchers use grounded theory studies to synthesize a new theory.

The choice of method or approach for a meta-synthesis is informed by the purpose and epistemological position but also the nature of the evidence in the

field. If the evidence is mainly descriptive and there are no established theoretical models for understanding the phenomena, an inductive approach such as critical interpretative synthesis may be useful. In cases where the evidence is extremely theorized or conceptual, framework synthesis could be employed. Studies selected for synthesis that are heterogeneous may not allow an understanding to be built of one study in the light of another, a process known as reciprocal translation. A thematic synthesis, therefore, may be more appropriate than meta-ethnography (see ► [Chap. 48, “Thematic Analysis”](#)). If the research reports selected for synthesis do not provide “thick” data, then a meta-summary may be more appropriate than grounded theory. The choice of method will also depend on the expertise of the research team, the available financial resources, and time.

4 Practical Approaches to Undertaking a Meta-synthesis

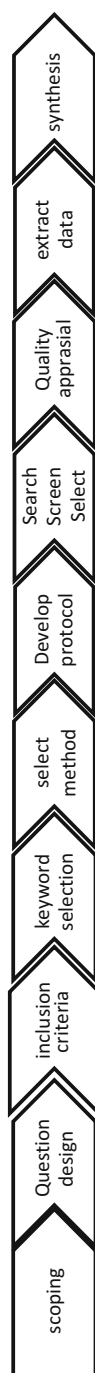
There are many key steps (see [Fig. 4](#)) involved in undertaking a meta-synthesis that are not discrete but rather are iterative and may be constantly revised.

4.1 Defining the Scope of the Study

Scoping at the early stages of a meta-synthesis is necessary to determine the feasibility of undertaking a synthesis, the nature of the literature, and the resource implications. This process in turn will help to define the review question, the method of synthesis, and search terms or keywords, identify relevant databases or other repositories of research, and develop the inclusion/exclusion criteria for the screening and selection of research reports. Scoping involves preliminary searches of literature, reading, and discussions with experts to clarify research questions and identify papers that can provide theoretical insights, a priori frameworks, or conceptual leads that can provide a useful starting point for analysis. Ongoing discussion is required with the research team to make decisions about how the study should be designed and undertaken so that a protocol for the study can be developed.

4.2 Question Design

There are various approaches and tools that may be useful to guide question formulation whether it be an effectiveness question, an exploratory one, or a question designed to generate theoretical insights ([Harris et al. 2017](#)). Different approaches include the PICOS (Population, Intervention/phenomena of interest, Control, Outcome, and study design) model ([Hannes and Pearson 2012](#); [Dawson et al. 2013](#)), the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool ([Cooke et al. 2012](#)), the SPICE (Setting, Perspective, Intervention/Exposure/Interest, Comparison, Evaluation) tool, or the CHIP (Context, How, Issues, Population) tool ([Shaw 2010](#)). An example of the use of the PICOS approach

**Fig. 4** Key steps

can be seen in a narrative synthesis on task shifting in reproductive health (Dawson et al. 2013). The question was defined by identifying the following key areas:

- Population: medical doctors, doctor assistants, nurses, midwives, auxiliary nurses, auxiliary midwives, and community health workers and lay health workers in low- and middle-income countries
- Intervention: worker substitution, delegation, and task sharing across teams
- Outcome: clinical performance, patient outcomes, training outcomes, provider needs and experiences, and cost-effectiveness
- Study design: qualitative studies, observational studies, quasi experimental and nonexperimental descriptive studies

The final review question therefore was: “For health-care providers in low- and middle-income countries, how have task-shifting interventions influenced the provision of reproductive health care and the capacity and needs of providers?”

The use of the SPIDER mnemonic to guide question development and the inclusion criteria can be seen in the narrative synthesis by Oishi and Murtagh (2014) that sought to identify the challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community. The question was defined by clarifying the following:

- Sample: patients with life-limiting diseases other than cancer, carers, health-care professionals
- Phenomenon of interest: primary palliative care for non-cancer patients at home
- Design: any design
- Evaluation: the views of patients
- Research type: any design

4.3 Developing an Inclusion Criterion and Forming Keywords

Clarifying the review question is important to identifying both the criteria that will be used to screen the papers and the keywords that will be used to direct the search for the literature. Table 1 describes the inclusion/exclusion criteria that was developed and applied to the screening of papers for a content analysis of qualitative and quantitative evidence (Dawson et al. 2015). This study aimed to identify approaches to improving the contribution of the nursing and midwifery workforce to increasing universal access to primary health care for vulnerable populations. For example, papers were included in the initial screening if the studies they reported were focused at the primary health-care level and the interventions were led by nurses and/or midwives.

Keywords can be identified from both the question definition and the inclusion criteria. A research librarian can be helpful to assist the study team to identify standard keywords used in specific databases and the Boolean operators (and, or, not) that can be used to connect and define the relationship between your search terms. Using the relevant MESH (Medical Subject Headings) as keywords will also help to optimize the search to ensure the retrieval of relevant literature. MESH is a comprehensive standard

Table 1 The inclusion/exclusion criteria applied to the screening of papers

Included	Excluded
Primary health care	Hospital-based care
Nurse-/midwifery-led health delivery	Care delivered by doctors, community, or lay health workers
Study participants: vulnerable population groups	Study participants: general population, high socioeconomic index
Interventions included nurse/midwife education/training and/or increase in supply and/or human resource management (HRM) strategy and/or policy/practice change and/or collaborative partnership arrangements	Interventions did <i>not</i> include nurse/midwife education/training and/or increase in supply and/or HRM strategy and/or policy/practice change and/or collaborative partnership arrangements
Outcomes included improvement in acceptability/satisfaction/uptake of services and/or service quality and/or health outcomes and/or nurse/midwife capacity to promote, care, and manage health issues	Outcomes did <i>not</i> include improvement in acceptability/satisfaction/uptake of services and/or service quality and/or health outcomes and/or nurse/midwife capacity to promote, care, and manage health issues
Primary research	Discursive or descriptive outlines of projects
English	Non-English
>2005	<2005

vocabulary for indexing journal articles that was established by the National Library of Medicine in the United States. They are constantly revised and updated. MESH, therefore, serves as a thesaurus that facilitates searching databases such as PubMed[®]. The keywords at Table 2 were used to retrieve literature from eight bibliographic databases for a content analysis discussed above (Dawson et al. 2015). This includes examples of MESH keywords and nonstandard keywords that were combined with the Boolean operator “and” to retrieve 111 records that were screened using the inclusion criteria at Table 1 to identify 115 records.

4.4 Selecting a Method or Approach to the Synthesis of Qualitative Data

As previously discussed, the approach for the meta-synthesis is dependent upon the purpose of the review, the position and paradigm, the nature of the current evidence, the expertise of the team, and available resources. The choice of content analysis to identify approaches to improving the contribution of the nursing and midwifery workforce to increasing universal access to primary health care for vulnerable populations in the study by Dawson et al. (2015) was based upon initial scoping and the purpose of the paper that was undertaken in partnership with the World Health Organization. A directed approach was deemed the most useful as the findings were to be employed to develop a plan of action at a Global Forum for Government Chief Nursing and Midwifery Officers. A conceptual framework was, therefore, developed to clearly articulate the workforce and leadership interventions that research had identified as contributing to increasing access to universal health care.

Table 2 Search terms applied to the database search for literature

	Search terms
	Nursing, nurse
and	Midwifery, midwife
and	Leadership
and	Policy
and	Universal access, effective coverage, equitable access, health-care access, appropriate health care, acceptable health care, health equity
and	Quality, availability, accessibility, acceptability
and	MESH heading “manpower” “Nursing” “Primary Care Nursing” “Maternal-Child Nursing” “Public Health Nursing” OR “Primary Nursing Obstetrical Nursing”[Mesh] OR “Nursing, Team” “Nursing Staff” “Midwifery” “Nurse Midwives” “Policy” “Universal Coverage”
	Primary health care, community health
Study type	
Date of publication	2003–2015

The data was, therefore, extracted, categorized, enumerated, and synthesized according to the elements of this framework. This approach enabled the findings to be immediately utilized for decision-making in multiple contexts. However, theorizing is largely absent and limited by the lack of rich detail of the original study contexts.

4.5 Developing a Protocol

A protocol is necessary to articulate clearly the study objectives and methods that serve as a point of reference to guide the implementation of the review, which ensures rigor and quality control and can be registered to promote transparency, avoid the duplication of reviews, and assist others to locate the research easily. Meta-synthesis registration can occur with organizations such as the Cochrane Collaboration, the Campbell Collaboration, or PROSPERO, an international database of prospectively registered systematic reviews where the outcome concerns health.

4.6 Technology to Support Meta-synthesis

Technology is useful to support the design of meta-synthesis, database searching, screening, appraisal, and analysis. This includes tools produced by the Cochrane Collaboration (RevMan and Covidence), QARI (Qualitative Assessment and Review) software developed by the Joanna Briggs Institute (JBI), and EPPI-Centre (Evidence for Policy and Practice Information and Co-ordinating Centre) Reviewer 4: software for research synthesis. There are also a number of tools for qualitative data analysis such as text mining tools (Thomas et al. 2011) including those to categorize research into themes (Stansfield et al. 2013) and other standard qualitative data management

softwares QSR NVivo and ATLAS.ti (see also ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”).

4.7 Searching and Selecting/Sampling Studies

Decisions will need to be made concerning the approach to the selection of evidence in terms of either a comprehensive, purposeful, theoretical, or random sample of studies to be included in the synthesis. This decision will determine the number of studies included and depend on the purpose of the synthesis, the epistemology, and the available evidence clarified in the inclusion criteria. As noted above, if the evidence is mostly descriptive and the aim is to aggregate all available data, then a comprehensive approach may be appropriate involving many studies. However, if the aim is specific, then techniques such as stratified, snowball, or criterion sampling may be undertaken. For example, if human-lived experience is sought with a focus on personal consciousness and research reports are available, then a purposive selection of phenomenological studies may be relevant, such as the synthesis by Röing et al. (2017). Searches undertaken with the aim of theoretical inquiry are based on key concepts that are relevant to researchers, and attention is focused on inconsistent findings or similar study populations that are of conceptual relevance. Theoretical selection is iterative; the aim is to draw upon what is previously known to identify and examine the complexity of different conceptualizations. Selection is constantly refined until no new data is revealed. Whatever the approach, it must be demonstrated that the findings of the synthesis are well supported by adequate raw data such as participant quotes, observations, and so on.

Some researchers may make the decision to only search for peer-reviewed primary research papers in electronic databases using standard keywords with added hand or manual searching of reports based on references identified in selected research papers. Other researchers may extend their search to gray literature if the field is an emerging one and insights are to be gained from unpublished research reports. This can include documents from websites of organizations, online libraries such as the World Health Organization’s Reproductive Health Library, meta-indexes, or a locally hosted website where there are collections of Internet resources on specific topics, electronic gateways (i.e., <https://knowledge-gateway.org/>), or data obtained from contacting the authors of research. Researchers may also seek data from these sources using nonstandard keywords. There is no consensus on the best data sources for meta-synthesis, and the decision should be well justified and information retrieval methods clearly articulated and documented using a diagram known as PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) guidelines (Moher et al. 2009).

4.8 Appraising Qualitative Studies in the Review

Assessing the methodological quality of studies is one consideration in the process of deciding whether a study should be included or excluded from the synthesis.

Excluding methodological “weak” studies have not demonstrated to affect the results of a synthesis; however removing papers based on their methodological limitations can result in the loss of contextual or deviant data that might be useful to the synthesis findings. Therefore, the final decision regarding a paper’s inclusion/exclusion must involve an explicit sensitivity analysis and consensus among the research team. Standard tools for appraisal include the United Kingdom’s National Health Service Critical Appraisal Skills Programme (CASP) qualitative checklist and the JBI QARI Critical Appraisal Checklist (see also ► [Chap. 58, “Appraisal of Qualitative Studies”](#)). However, the latest Cochrane advice recommends the use of tools that focus on an assessment of methodological strengths and limitations of the research report (Noyes et al. 2017). This includes an assessment of the available detail on the data sampling, collection, and analysis processes and the coherence of the paradigm underpinning the study involving the fit between data gathered and the conceptual work of analysis and interpretation.

4.9 Extraction and Synthesis Processes

Once papers have undergone quality appraisal, data for the included studies will need to be systematically extracted for analysis, and the approach to this will again depend on the purpose, epistemological position, and paradigmatic worldview chosen by the researchers. First, the researcher will need to decide what constitutes qualitative data to be extracted and from what sections of the research report this data is to be extracted. The qualitative data may only include data pertaining to the findings sections of the papers such as qualitative quotations of participants, data from tables, photographs, diagrams, or quotations from researcher’s field notes or recorded observations or the themes, sub-themes, and associated explanations. However, other researchers such as those undertaking a meta-ethnography may see data from the whole text itself including the title, abstract, introduction, and discussion. Supporting materials may also be included such as correspondence, interviews, or discussions with researchers about the study via email, video, or mobile phone (Onwuegbuzie et al. 2012). The rationale for the inclusion of multiple data may be to ensure adequate meaning is generated and, therefore, contributing to the quality and rigor of the synthesis. Despite the approach, research must articulate how and why data was extracted and integrated. These processes must be transparent, and an audit trail should be available documenting the logic of the analysis so that decision-making is traceable. This can be achieved through the use of standard forms and templates and frameworks developed from conceptual/theoretical models, logic models, or iteratively using qualitative data analysis tools such as NVivo (Noyes et al. 2017; see also ► [Chap. 52, “Using Qualitative Data Analysis Software \(QDAS\) to Assist Data Analyses”](#)).

A meta-synthesis will involve two types of data analysis within-study analysis to help contextualize the findings across study analysis and synthesis. One of the key processes involved is reciprocal translation where researchers read within studies and across them to understand how studies relate, build upon, or differ from

each other and knit this together in a critical manner. The approach to this can be linear and aggregative in line with meta-summary or iterative in the case of meta-ethnography. Melendez-Torres et al. (2015) have identified four approaches to reciprocal translation: visual representation, key paper integration, data reduction and thematic extraction, and line-by-line coding. Furthermore methods and tools to integrate qualitative and process evaluation evidence within intervention effectiveness reviews have recently been identified by CQIMG (Harden et al. 2017). Harden et al. have noted that in these pragmatic syntheses, researchers can either undertake a sequential or separate analysis of qualitative evidence and quantitative evidence and then integrate the data or take a convergent approach where themes and outcomes are integrated from the start using a common framework.

5 Conclusion and Future Directions

Over time, the rigor of reviews has been found to increase with search procedures, quality appraisal, and synthesis procedures more clearly articulated (Hannes and Macaitis 2012). Guidance on these processes is also more available such as those provided by the CQIMG and the increasing number of papers and handbooks demonstrating a variety of approaches that serve as points of reference for other researchers. Standards for the reporting of syntheses have emerged such as the generic tool for reporting qualitative meta-synthesis (Tong et al. 2012) and specific methodological guidance for the reporting of realist and meta-narrative reviews (RAMESES) (Wong et al. 2014). New tools are in development for meta-ethnographies (France et al. 2015), and it may only be a matter of time before these become available for other approaches such as formal grounded theory and critical interpretative synthesis. However, a balance must be made between the soundness of reporting and the innovation and creativity of approach that demands that these standards remain flexible.

A necessary element of conducting a meta-synthesis is updating the review to keep the findings current to health-care policy and practice. There is a lack of guidance on updating the meta-synthesis of qualitative evidence, a requirement if registered with Cochrane or PROSPERO. France and colleagues (2016) outline a structured approach to updating a meta-ethnography both in terms of deciding when an update is necessary and how this should be undertaken. The authors identify the characteristics of various approaches including reviews that focus on revising the original, undertaking a separate and independent review that can serve as a comparison or declare the original defunct and redo the review. In addition, France et al. provide some guidance for those appraising the update both in terms of the rationale for undertaking an update and the process and methods applied. While other authors have trialed these guidelines (Rodríguez-Prat et al. 2017), gaps remain in terms of updating other methods from different paradigms.

While tools have been developed to guide within-study quality appraisal and insights to support across-study quality meta-synthesis and the reporting of these, an approach to assessing the confidence in the findings of meta-syntheses is relatively recent. The GRADE-CERQual approach (Grading of Recommendation, Assessment,

Development, and Evaluation-Confidence in the Evidence from Qualitative Reviews) has been developed to ensure that evidence syntheses focused on providing evidence to inform health service or care decision-making processes are conducted and reported in a transparent manner. This tool enables an assessment of a meta-synthesis based upon:

the methodological limitations of the qualitative studies contributing to a review finding, the relevance to the review question of the studies contributing to a review finding, the coherence of the review finding, and the adequacy of data supporting a review finding. (Lewin et al. 2015, p. 1)

The CERQual approach is the qualitative equivalent of the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach for evidence of effectiveness for quantitative meta-analysis. The tool provides a structured means to interrogate how issues in the design and conduct of the primary studies in a synthesis impacted upon the findings and the relevance of these study findings are to the context specified in the review question. In addition, the tool also assists with an investigation of the extent to which the synthesis is based upon the findings of the primary studies that are convincingly and adequately represented in the synthesis findings. Lewin et al. (2015) provide an example of how the tool can be used to generate a narrative to provide an overall CERQual assessment of confidence and an explanation of this judgment. However, this work is still in development along with the Cochrane qualitative Methodological Limitations Tool (CAMELOT) for use with the first component of CERQual. While CERQual has been tested largely on synthesis using framework analysis or narrative synthesis approaches (Chatfield et al. 2017), its use with synthesis that employ theory generation or interpretative approaches is yet to be seen.

Another area under investigation is the mega-synthesis of meta-syntheses. Tomlin and Borgetto (2011) developed a three-dimensional model to describe different levels of evidence to inform occupational health practice. Mega-synthesis has been argued to be the highest level of evidence in Tomlin's model. This, according to Tomlin et al., is achieved when there is a convergence of meta-synthesis and meta-analysis or when high-level/internally and externally valid qualitative, experimental, and outcome evidence meet. Hannes et al. (2015) have instead proposed a four-dimensional model with mega-synthesis in the center that promotes a question-led approach to synthesizing evidence from both external evidence (qualitative and quantitative scientific) and internal evidence from the experience and needs of clinicians, patients/consumers. They argue that review questions should be driven by what matters rather than what works. This highlights the importance of an inclusive reasoning process, not tiers of evidence informed by study methods such as randomized control trials to achieve treatment choices and inform shared decision-making. Mega synthesis, therefore, is a process where the internal evidence base is the starting point from where the available and relevant external, research-driven evidence base can be used to inform coherent decision-making. This approach to mega-synthesis then takes us back to the principles of the patient-centered movement, to ensure that evidence and decision-making process are directed by the health needs of the community together with health professionals, rather than by the medical establishment.

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Conducting a Systematic Review: A Practical Guide

46

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Contents

1	Introduction	806
2	Stages of a Systematic Review	808
3	Constructing the Research Question	808
4	Conducting a Scoping Search	809
5	Developing a Systematic Review Protocol	811
6	Searching for Relevant Literature	812
7	Managing Citations	813
8	Documenting the Characteristics of Included Studies and Summary of Findings	814
8.1	Participants	815
8.2	Methods	816
8.3	Intervention Characteristics	816
8.4	Outcomes	816
8.5	Additional Characteristics for Qualitative Studies	817
9	Data Extraction	817
9.1	What to Extract	817
9.2	Data Extraction Forms and Databases	817

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805

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9.3	Software	818
10	Methods for Assessing Risk of Bias and Considering Heterogeneity	818
10.1	Measuring Study Quality	818
10.2	Heterogeneity	819
10.3	Risk of Bias Tools	819
10.4	When Risk of Bias Measurement May Need to Be More Flexible	820
11	Meta Analyses	820
11.1	What Is Meta-analysis?	820
12	Creating a Narrative and Interpreting Findings	822
13	Conclusion and Future Directions	824
	References	825

Abstract

It can be challenging to conduct a systematic review with limited experience and skills in undertaking such a task. This chapter provides a practical guide to undertaking a systematic review, providing step-by-step instructions to guide the individual through the process from start to finish. The chapter begins with defining what a systematic review is, reviewing its various components, turning a research question into a search strategy, developing a systematic review protocol, followed by searching for relevant literature and managing citations. Next, the chapter focuses on documenting the characteristics of included studies and summarizing findings, extracting data, methods for assessing risk of bias and considering heterogeneity, and undertaking meta-analyses. Last, the chapter explores creating a narrative and interpreting findings. Practical tips and examples from existing literature are utilized throughout the chapter to assist readers in their learning. By the end of this chapter, the reader will have the knowledge to conduct their own systematic review.

Keywords

Systematic review · Search strategy · Risk of bias · Heterogeneity · Meta-analysis · Forest plot · Funnel plot · Meta-synthesis

1 Introduction

One of the key principles in evidence-based practice is the synthesis of all available evidence on a particular research topic. As there has been exponential growth in the volume of scientific research over the last few decades, a method to synthesize this evidence has become necessary. For some time, literature or narrative reviews have been used to give a broad overview of a particular research topic. Typically, these types of literature or narrative reviews refer to a number of articles published within a research topic area and can give a reasonable description of an issue. Literature or narrative reviews are generally considered to be opinion pieces as they usually do not systematically search the literature and instead often focus on a small group of relevant studies in a chosen area, based on author selection (Uman 2011). Following this process, selection bias can be introduced into this type of review. This is what

makes systematic reviews distinct from narrative and literature reviews as (using multiple investigators to ensure rigor) systematic reviews use explicit, structured, predefined methods to identify all relevant literature and to minimize risk of bias (Koelemay and Vermeulen 2016).

Systematic reviews should, therefore, have a clear definition of inclusion and exclusion criteria, feature a wide-ranging search which identifies all relevant literature, use explicit and reproducible selection criteria for included studies, have a rigorous appraisal of potential biases in the included studies and systematically synthesizes results of the included studies (Cook et al. 1997). This is why systematic reviews have been adopted as a more trustworthy and robust means of synthesizing the available evidence on a particular research topic (Mulrow et al. 1997).

When well conducted to ensure high quality, systematic reviews are considered to be one of the highest forms of scientific evidence to inform recommendations for health promotion, intervention design, policy development, and best practice approaches in health (Moher et al. 2015). Systematic reviews can be complicated to conduct however, with quality largely dependent on the type of studies available on a particular topic, research methodology, the outcomes measured, and the quality of reporting. The best quality systematic reviews summarize results of intervention studies (e.g., randomized controlled trials), but sometimes due to a lack of evidence in a particular field, a systematic review may also include other study designs. For example, a systematic review could collate evidence on the effectiveness of diagnostic tools, on the findings of observational studies, or on qualitative studies. Historically, systematic reviews have been conducted on quantitative data. More recently, systematic reviews on qualitative data have been increasing in popularity; the process by which qualitative data are synthesized is called a meta-synthesis (see also ► Chap. 45, “Meta-synthesis of Qualitative Research”).

When conducting a systematic review, authors develop detailed search strategies that are carried out in several discipline-specific databases. Potentially relevant articles are rigorously screened against a set of inclusion and exclusion criteria. Data are then extracted from all included research articles and study quality is assessed by exploring potential risk of bias in relation to study design. The authors will then make use of this evidence to make an overall judgment about the effectiveness of the findings of the included studies weighted by study quality. Sometimes, effect sizes from two or more included studies can be combined quantitatively to give an overall combined measure of effect. This pooling of statistical data is called a meta-analysis (Cook et al. 1997). A meta-analysis can usually give a more accurate idea of the overall effect of the combined studies. However, often it is not possible to quantitatively combine results of included studies due to variance in the reporting of outcomes (e.g., missing information from papers required for pooling data), or incomparable tools used to measure efficacy of an intervention across papers (e.g., some self-report vs. objective measurements). Quantitative systematic reviews can, therefore, also be narrative, where the results of the combined studies are synthesized descriptively. Both of these methods alone or in combination are able to summarize existing research on a particular topic.

Systematic reviews can improve not only dissemination of evidence but may also help in examining heterogeneity in results of different studies, make overall findings more generalizable, improve understanding of a particular research issue, and guide practice and policy decision-making (Cook et al. 1997; Greenhalgh 2010).

2 Stages of a Systematic Review

A methodologically sound systematic review consists of several stages:

1. Constructing the research question
2. Scoping search
3. Protocol development
4. Comprehensive and systematic search
5. Selection of studies against eligibility criteria
6. Data extraction
7. Appraisal of studies using a quality checklist
8. Analysis of results
9. Interpretation of findings
10. Dissemination

For the remainder of this chapter, each of these stages will be discussed.

3 Constructing the Research Question

Before beginning a systematic review, it is important to have a clear focus as this will guide decisions on search terms, the databases to be used, and the main types of research studies to be included. Once this has been established, it is necessary to formulate clear, unambiguous, and structured questions. A PICO structure is the most useful method of creating an appropriate and specific review question. PICO is defined as

- Population, participants, patient or problem
- Intervention(s), therapy, treatment
- Comparison (other intervention or treatment, control group)
- Outcome(s)

For example, if you were interested in a review on the impact of breast screening on the early detection of breast cancer in women, your PICO could look like this:

P	—	women
I	—	breast screening
C	—	no intervention
O	—	early detection of breast cancer

In some cases, a PICO question may also have the addition of the study design, making it a PICOS question.

4 Conducting a Scoping Search

Once a clear focus and PICO question have been developed, the next step is to conduct an initial scoping search of the literature. A scoping search is a basic, fairly brief search of the existing literature that will give an idea of the breadth of studies on a chosen topic, and whether a systematic review has already been conducted on the same topic. If another systematic review has already been published recently, you may choose to look at the literature from a different perspective, for example, you may focus on a different patient group. A scoping search will help shape the final research question, identify relevant search terms (by checking the titles and abstracts of the papers found in your scoping search), and develop inclusion/exclusion criteria for the systematic review. Additionally, the search will help to identify the quantity of primary research on the topic to inform the scale of the review. Last, a scoping search can help in identifying key papers on a chosen topic so that once the main search begins, it is possible to check the effectiveness of the search strategy in finding those key papers.

To conduct a scoping search, a search strategy that includes all potential synonyms for key search terms needs to be developed. For example, if a search was being conducted to identify breast screening programs, authors may use alternate terms such as “mammograms” or “cancer screening” instead of “breast screening.” These additional search terms should be included the search strategy (see Table 1).

The next step is to select resources relevant to the research topic area that should be searched. These resources should provide access to all types of literature including systematic reviews, clinical guidelines, and primary research. For health-based systematic reviews, using databases such as the Cochrane Library (to search for systematic reviews), National Institute for Health and Care Excellence (systematic reviews, clinical trials, clinical guidelines), Turning Research Into Practice (systematic reviews, clinical trials, clinical guidelines, primary research), and MEDLINE (systematic reviews, clinical trials, clinical guidelines, primary research) is recommended.

Each database is different, so it is important to be familiar with the platform selected before searching is started. The search may need to be adjusted slightly with each database to ensure the most relevant results are yielded. A minimum of two to three databases should be selected to ensure access to a wide range of resources. In each database, it is also important to be familiar with the correct use of truncation, Medical Subject Headings (known as MeSH headings), wildcard features and Boolean operators (see Table 2), which will make searching more efficient and

Table 1 Example synonyms for a PICO search relating to breast cancer screening in women

	Search terms
P	Middle-aged women, women, females, postmenopausal women
I	Breast screening, mammogram, cancer screening
C	No mammogram, no intervention
O	Early detection, breast cancer, early diagnosis

Table 2 Using truncation, MeSH, wildcards, and Boolean operators in a search strategy

Truncation	Truncation is a technique to broaden a search to include various word endings and spellings. To use truncation , enter the root of a word and put the truncation symbol at the end. The database will return results that include any ending of that root word. Commonly used truncation symbols are * and \$, but these vary between databases
MeSH headings	MeSH headings are a comprehensive controlled vocabulary used to index journal articles and books in the life sciences and can also be used as a thesaurus when creating alternate keywords. Different databases may have different terminology for their medical headings (e.g., in the Current Nursing and Allied Health Literature (CINAHL), they are called CINAHL headings)
Wildcard	Wildcards are a method of searching for alternative spellings of the same words. For instance, there are a number of words that are spelt differently in the United States versus the United Kingdom, such as organization (organisation in the UK) and pediatric (paediatric in the UK). To use the wildcard feature, simply substitute the wildcard symbol, which is often "?", to replace a missing letter. For example, you could search for "organi?ation" to capture both "organization" and "organisation"
Boolean operators	<p>After identifying all relevant keywords, synonyms, and phrases within a search, Boolean operators need to be used to combine topic areas together. The Boolean operators are "AND", "OR", and "NOT".</p> <p>Using OR combines all the individual synonym terms together into one search and broadens your results by including references that have ANY ONE of the search terms within it</p> <p>Using AND focusses the search by combining keywords to find references that contain ALL of the keywords, to narrow your search</p> <p>Using NOT will eliminate items and limit a search further</p>

thorough. Information on how to apply these can usually be found in the help sections of each database. It is also important to create an account for each database as this will allow searches to be saved and the creation of alerts based on the search strategy to be set up.

The scoping search should then be run in each database. It is important to note each of the search terms used and the total number of hits for each search. Saving a search to an account is a good way to keep track of searches. Once this is done, a scan through the titles of the papers identified in the scoping search should be undertaken, and citations downloaded for relevant papers. It is also useful to save the pdf of each paper in a designated "scoping search" folder or reference manager library, such as in EndNote. Reading the abstracts and papers is not too important at this stage – only complete a quick scan of the abstract if there is uncertainty about the eligibility of a particular paper based on the title. The scoping search will provide you with an estimate of the number of papers available on a particular topic and will allow you to make modifications to your search strategy. Irrelevant papers may also have been found that are not necessarily relevant to the current PICO question. It is usual to have captured some irrelevant papers, but if these make up the majority of your returned hits, then there are several ways to deal with this:

- Revision of the synonyms used – the search may have been too broad. Remove one search term at a time and record the number of hits. There may be specific terms that are expanding your search considerably and away from your PICO question.
- Use the “NOT” Boolean operator to exclude a specific search term from the search.
- Create a scoping summary table. This table does not require as much detail as the table to be created from the formal systematic review search. In the table, enter the following information from the papers found:
 - Authors, year of publication, title of paper, trial/program name (in case multiple papers report on the same trial), aim of the study.
 - This information can be inserted directly from the abstract as the purpose of this phase is to provide scope of the papers that should be identified in the formal search.

Use this table to explore patterns across studies and how you might refine the search if you are returning too many hits.

Following the above steps, elements of the PICO(S) question will then be refined to determine the specific inclusion and exclusion criteria that will be used to select studies for inclusion in the review.

5 Developing a Systematic Review Protocol

Systematic review protocols help assure that decisions made during the review process are not arbitrary and that decisions to include or exclude studies are not made with knowledge of individual study results. A systematic review protocol should describe the rationale, hypothesis, and planned methods of the review, including the research question. A protocol should always be prepared before the review is started and be used as a guide throughout the review. Several guidelines for preparing a systematic review protocol are available including the Preferred Reporting Items for Systematic review and Meta-analysis extension for Protocols (PRISMA-P) (Moher et al. 2015) and The Cochrane Handbook of Systematic Reviews (Higgins and Green 2011).

Following PRISMA-P guidelines (Moher et al. 2015), the protocol should include the following:

1. Introduction
 - (a) **Rationale** described for the review in the context of what is already known about the topic
 - (b) An explicit statement of the **research question** including PICO(S) terms
2. Methods
 - (a) **Eligibility criteria** should be specified for report characteristics (language, publication status) as well as study characteristics. These should be based on your PICO question, considering all aspects of the topic including age groups, geographical areas, study designs, illness stage (if applicable), and any outcome measures. Clear eligibility criteria make it easier to identify

- relevant articles at the screening stage. Be wary of date range limits; these must be justifiable.
- (b) All **information sources** should be described (databases to be used, personal communications, use of trial registers, grey literature sources) with anticipated dates of coverage.
 - (c) A draft of the **search strategy** that will be used in at least one database should be presented, including limiters, so that the search can be repeated.
 - (d) A description of how data and records will be **data managed** throughout the review.
 - (e) The **selection process** for study inclusion and exclusion (e.g., two independent reviewers) for each part of the review must be described (screening, eligibility, and inclusion in meta-analysis).
 - (f) The planned **data collection process** method must describe data extraction methods (e.g., was this done independently, and were data extraction forms used to ensure consistency) as well as processes for obtaining and/or confirming data with study authors.
 - (g) Any pre-planned **data assumptions or simplifications** should be listed and defined.
3. **Outcomes and prioritization** must be listed including a definition and list of all outcomes for which data will be sought and prioritization of primary and secondary outcomes detailed.
 4. The proposed methods should be detailed for assessing **risk of bias** and how the information will be used at the data synthesis stage.
 5. **Data synthesis** methods need to be described, including the following:
 - (a) Criteria for which studies will be **quantitatively synthesized**.
 - (b) Where data are appropriate for quantitative synthesis, planned summary measures, data handling and combination methods as well as heterogeneity exploration methods.
 - (c) Any proposed **additional analyses**, such as sensitivity or subgroup analyses
 - (d) Where quantitative analysis is not feasible, the type of summary planned.
 6. Any **planned assessment of meta-biases**, for example, publication bias, should be described.
 7. Confidence in cumulative evidence should be outlined with a description of how the body of evidence will be assessed.

The systematic review protocol should be adhered to throughout all stages of the review with any amendments to a protocol tracked and dated.

6 Searching for Relevant Literature

Once a search strategy has been generated from the research question, a scoping search has been undertaken, and eligibility criteria (inclusion/exclusion criteria) have been developed and refined, the formal systematic review search can then be conducted. The advanced search strategy for the systematic review will need to be

Table 3 Example of a search conducted in the MEDLINE database

P	AB Mid†* age* wom#n OR AB wom#n (S1)
I	AB Physical activity* OR AB sport* OR AB fitness OR AB walk* OR AB exercise (S2)
C	AB control OR AB usual care OR AB no intervention
O	AB Type 2 diabetes OR AB diabetes OR AB T2DM OR AB diabetes mellitus OR diabetes management (S3)
Final Search	S1 AND S2 AND S3

Note: AB, Abstract; *, Truncation; #, Wildcard; S, Search; P, Population; I, Intervention; C, Comparison; O, Outcome

finalized for each database, using appropriate MeSH terms, wildcards, truncation, and Boolean operators. An example of an advanced search strategy for MEDLINE (looking for the selected words in abstracts) is detailed in Table 3 for the research question: Is physical activity effective for the management of type 2 diabetes in middle-aged women compared to usual care?

As with the scoping search, logging into each database before conducting your systematic searches allows for a record of the search to be saved, and for alerts to be configured. As systematic reviews can take several months to prepare, it is important for database alerts to be enabled so that authors can be notified when any new studies matching their search strategy are added to a database. Again, as with the scoping search, limiters may also be applied before searching (e.g., publications in English only, publication dates, full text availability, searching abstracts only, and so on). Note that in some instances, you may not need to include comparison or outcome terms – removing these terms will widen your search. All databases should be searched within the same week to ensure consistency. A summary table is useful for keeping track of the search strategy (and slight variations between databases), including synonyms and MeSH terms, limiters, dates of searches, and number of hits for all databases that you have searched.

Librarians are a useful resource to advise on the selection of databases and should be consulted in this process. There is no consensus on the number of databases that should be searched, but rather the final selection should allow for a wide net to be cast to pick up the majority of studies on the chosen area. Citation and reference list searches can also be conducted on identified eligible studies and experts in the area can be consulted, to help find any additional papers not captured by the initial database searching. These additional steps will help to minimize the possibility of published work being overlooked.

7 Managing Citations

Conducting scoping and systematic searches can produce a large number of references that can be difficult to manage and categorize. Having a systematic approach to managing citations can not only make the sorting process less logistically

challenging, but it can also improve the rigor and reproducibility of the results. There are a range of different citation management (bibliographic) software tools available that can facilitate this process, for example, EndNote, Mendeley, Refworks, and Review Manager. Once the search results have been downloaded from each database, citation management tools can be used to automatically remove duplicates and to sort and categorize results during the screening process. Note that citation management tools often do not capture all duplicates for removal, but this automatic process can help to speed up the process of duplicate removal considerably.

The PRISMA statement (Moher et al. 2009) provides a similar set of guidelines to the PRISMA-P statement (Moher et al. 2015) described above. The PRISMA statement focuses on the reporting of systematic reviews rather than protocol development, and recommends including a flow diagram detailing the study selection processes through each stage of the review (e.g., number of hits identified from databases, number of papers meeting eligibility criteria, selection of studies for final inclusion, and so on). Citation management software is, therefore, a useful and powerful tool in the organization and screening of large numbers of references, and ensuring that data are reported correctly for the PRISMA flow diagram (King et al. 2011). Tools in EndNote such as Groups, Smart Groups, Group Sets, and Labels can be particularly useful for categorizing references. For example, Groups may include all publications within a certain year range (e.g., 2005–2010 and 2011–2015); these can be combined using a Publication Date Group Set (Peters 2017). Groups are useful to file citations into include, exclude, and uncertain categories, for transparency of the review flow with the wider review team. The review process to adhere to the PRISMA flow diagram requirements, as comprehensively detailed in Peters (2017), typically includes identification of studies, title and abstract screening of studies, eligibility of studies for inclusion (based on inclusion/exclusion criteria), eligibility for inclusion in meta-analysis based on methodological quality, and coding of included references (e.g., this could be done based on patterns of results: beneficial/detrimental findings from RCTs). Because citation management software such as Endnote also details the number of references in each Group, it simplifies the process of populating the PRISMA flow diagram and ensures the process is transparent and systematic.

8 Documenting the Characteristics of Included Studies and Summary of Findings

Once you have finalized your database searches and identified the articles that meet inclusion criteria for the review, you will need to document the characteristics of the included studies. The characteristics you document and report on should be relevant to your research question and the intended users of your systematic review (Higgins and Green 2011). Although the studies you deem eligible will typically focus on a similar population group, intervention, or outcome (depending on your research question and the focus of your review), not all studies follow appropriate recommended guidelines for reporting (e.g., the CONSORT statement for randomized trials (Moher et al. 2001; see also ► Chap. 56, “Writing Quantitative Research Studies”). It is, therefore,

Table 4 Information to be included in the *Characteristics of Included Studies* table

	Characteristics
Publication details	Author details Year of publication
Participants	Study setting (e.g., workplace) and location (country and city/town in which the study was conducted) Participant demographic profile, including age, sex, and any other specific information relevant to your review (e.g., body mass index, health status, presence or absence of disease, ethnicity)
Methods	Study design (e.g., randomized controlled trial), including details of group allocation and if and how the study differs from a standard parallel group design (e.g., cluster randomized trial) Study duration
Intervention characteristics (for intervention studies)	The name of the study or intervention (if applicable, to ensure you are reporting on unique interventions) Details of all intervention control groups For drug trials, include details of the drug, mode of administration, dose, frequency, and any other relevant information For intervention trials, include details of the mode and frequency of delivery, content of the intervention, and any other relevant information on intervention elements and materials
Outcomes	List all outcomes that are relevant to the review at each time-point and the tools used to measure outcomes

imperative that you develop a structured approach to collate and report on the characteristics of the included studies to ensure consistency in reporting. Such tables will aid you in writing the narrative section of your results. The following information in Table 4 should be (as a minimum) included in the “Characteristics of included studies” table:

8.1 Participants

When documenting the participant characteristics, it is important to include as much detail as possible to allow users of your review to determine the applicability of the study to the population group targeted. This information is also an important factor when comparing findings across multiple studies and unique population groups (Higgins and Green 2011), as heterogeneity in samples may explain some of the differences in findings. In this section, you should report details of the study setting and location, and any characteristics of the sample that are applicable to your review and the interpretation of the study results. For example, if you are conducting a review on the effectiveness of weight loss programs in culturally and linguistically diverse women, it may be important to report on characteristics including country of

birth, languages spoken at home, and year of arrival in the host country, if reported, as these characteristics may be associated with the outcome of interest.

8.2 Methods

To accurately report on the methods for each of your included studies, you must identify and report on the study design. If you are only including one specific study design in your review, for example, randomized controlled trials, it may not be necessary to include this information unless there are distinctions in design between the trials included. If you are including any studies with a pre- and post-test assessment, however, you may wish to include a column to detail type of study in your characteristics table (e.g., randomized controlled trials, nonrandomized experimental trials, or pseudorandomized controlled trials). In this case, it is important to specify between study designs as the users of your review will need to consider the rigor of the studies and hence quality of the results in relation to their research and population group.

8.3 Intervention Characteristics

When reporting on intervention characteristics, you should make note of the name of the intervention or program to help identify studies that have reported on the same study in multiple papers. This will prevent doubling-up on data extraction. Each individual study should provide enough detail on each intervention or treatment so that the study could be replicated (Higgins and Green 2011); you should be able to clearly describe the study and the characteristics of each group or treatment. For intervention trials, you should identify and report on the mode and frequency of intervention delivery (e.g., a 30-min face-to-face intervention delivered once per week for 12 weeks), details of facilitators (e.g., delivered by a trained exercise physiologist, general practitioners, community volunteers, or researchers), and details of intervention elements or materials (e.g., access to a mobile app or lifestyle peer support groups). In this particular phase, the focus is on providing the readers of your review with context. You will examine the quality of reporting for each study during the risk of bias phase, which is discussed in detail later in this chapter.

8.4 Outcomes

You may decide to only report on the outcomes that are relevant to your research question and review (Higgins and Green 2011). For example, if your review is focused on the effectiveness of workplace-based physical activity interventions and one of your included studies assessed physical activity levels, blood pressure, and psychological distress, you may decide to only include the results for physical activity as this will be most applicable to your review focus. You may also wish to consider only reporting on a specific time-point that is most relevant to the review, but the findings of each study would need to be interpreted in light of the time-points reported (e.g., did findings differ over the long-term compared to shorter interventions?).

8.5 Additional Characteristics for Qualitative Studies

Systematic reviews of qualitative studies will use a similar approach to that of quantitative studies, but should also include information relating to methodological underpinnings, data analysis techniques and approaches, and a more in-depth summary of the results including themes, quotes, and author interpretations (Butler et al. 2016). More detailed information on conducting systematic reviews using qualitative studies exists (see Dixon-Woods et al. 2006; Butler et al. 2016; see also ► Chap. 45, “Meta-Synthesis of Qualitative Research”).

9 Data Extraction

9.1 What to Extract

Prior to commencing data extraction, it is important to plan out carefully exactly what you want to gain from your review (this means thinking back to your research question). This will allow you to come up with a list of outcomes, intervention components, and data that you will identify from each included article. As well as the common descriptive characteristics detailed earlier, if you aim to undertake a meta-analysis, then extraction of outcome data will also be required. For qualitative reviews, extraction of themes relevant to your topic is necessary. Remember to check if authors have published associated protocol papers or supplementary online materials that might incorporate the information you are looking for. Authors can also be contacted to ask for any data not reported in a publication or to even provide a full data set.

9.2 Data Extraction Forms and Databases

Creating a standardized data extraction form is important to ensure that only data relevant to your review is extracted and that extraction is completed in a consistent manner across included papers and the research team. Prior to undertaking the full data extraction process, it is recommended that you trial your data extraction forms by having members of your research team extract data from one or two included studies. This will ensure that all relevant data is captured by your data extraction form, and will avoid having to re-visit papers multiple times to extract additional information. It is worth setting up an organized database or spreadsheet to store the information that you extract for your review. Although this might take some time to set up initially, it can save time in the long run by removing the need to refer back to individual papers and manually tallying up the number of papers reporting on a specific outcome. It will also make the process of reporting on extracted information narratively in your write-up, and the construction of summary information tables, quicker, easier, and more transparent for your co-authors. Existing software packages can be useful and are worth considering (see Sect. 9.3 below) or you might set up a simple Microsoft Excel spreadsheet, such as that pictured in Fig. 1. In this

	A	B	C	D	E	F	G
1	Lead Author & publication date	Population	Age (yrs)	Intervention duration (wks)	Follow up Duration (wks)	Num of intervention groups	Sample size (baseline)
2	MacMillan, 2016	Men	18-65	24	24	2	90
3	McBride, 2012 & 2014	Women	30-50	12	12	3	38
4	Steiner, 2012	Older adults	>65	12	24	2	1234
5	George, 2014	Children	5-12	24	104	2	408

Fig. 1 Example Microsoft Excel data extraction spreadsheet

figure, column headings represent study characteristics and outcome data to be extracted, with each row representing a different study included in the review.

Where you have identified more than one paper for the same study, it is important to clearly describe how you have dealt with the data extracted. For example, have you only included one row in your extraction sheet for all the papers identified related to that study or multiple rows, such as the McBride example above (there is a 2012 and 2014 paper associated with the same study)? Spreadsheets and databases can also be set up to assist you in reporting on study quality. For example, you may use a risk of bias tool to rate each study on a number of study quality areas. The questions used to decide on risk of bias ratings can be used as column headings to assist reviewers in the extraction of this information.

9.3 Software

The Systematic Review Tool box (<http://www.systematicreviewtools.com>) web-based catalogue includes links to tools that support all stages of the systematic review process. Literature reviewing softwares such as Covidence, GRADEpro GDT, Review Manager, and LitAssist include templates available for data extraction and can thus help speed up the data extraction process. For qualitative data extraction, software packages such as those used for individual qualitative studies (e. g., NVivo and Quirkos) can also be used to code data that will be summarized narratively in the results section of a systematic review. Other tools, such as EPPI-Reviewer, can be used for either quantitative or qualitative data synthesis. TaskExchange is software that bridges connections between those requiring assistance in completing a systematic review with experts in the conduction of reviews.

10 Methods for Assessing Risk of Bias and Considering Heterogeneity

10.1 Measuring Study Quality

Attempts to measure the quality of studies included in a review are necessary to interpret findings in respect to the strength of evidence (e.g., better designed, high-quality studies provide stronger evidence than poorly designed low-quality studies). It is often the case that studies with the poorest quality (poor methodology and study design) and highest risk of internal validity overestimate treatment effect size. It is, therefore, important to critically appraise studies (e.g., measure study quality) and

interpret findings in the weight of their risk of bias. If risk of bias is not taken into consideration, then the overall findings of a review are likely to be biased and may report that an intervention is effective when it is not, or ineffective when in fact it is.

This stage of a review involves selection, adaptation, or development of an appropriate tool to assess the risk of bias of the included studies. It is recommended that risk of bias ratings be completed by at least two raters independently to ensure a consistent and reliable process is followed. Ideally, this process should be undertaken following a blinded process so that raters are unaware of the authors of each included study that they assess. When assessing study quality, it is important to consider various sources of heterogeneity.

10.2 Heterogeneity

Differences in findings across studies with the same outcome measure can be due to a number of reasons. First, if a review is focused on determining effectiveness of a particular intervention, there may be differences in the delivery of the intervention that account for differences in the outcome achieved (e.g., cooking classes may be group-based, 30 min in duration and delivered by a dietitian twice weekly in one study vs. one-to-one, 60 min in duration and delivered by a community volunteer once weekly in another study). Second, demographic characteristics of samples of participants and baseline outcome values may differ across studies. Third, although the same outcome may be measured, the methods and tools to measure that outcome may be quite different across studies, with varying levels of validity and reliability in the target group (e.g., physical activity can be measured using objective measurement tools, such as accelerometers, and also using subjective tools, such as surveys and questionnaires). Fourth, setting may have an impact on outcomes achieved (e.g., a hospital-based yoga intervention vs. a community-based yoga intervention). Finally, the statistical analyses selected may impact on the conclusions drawn from the data. It is, therefore, important in any systematic review to consider the potential sources of heterogeneity and the impact heterogeneity may play on overall conclusions.

10.3 Risk of Bias Tools

There are many tools available to assess study quality. Some will produce scores, whilst others are checklists. Cochrane do not advise utilizing quality scales for the appraisal of clinical trials, but rather suggest the focus should be on methodological domains, which should be considered and tailored to the review (e.g., inclusion or exclusion, or more or less weight given to a particular domain based on the relevance of that domain to the review topic). Note that validity of a given tool will be affected by making amendments to it, but adjustments may be necessary to produce a more relevant tool for the studies included in the review. For example, several risk of bias tools include a measure of the quality of blinding participants to treatment group. This might be very applicable to some studies (e.g., clinical trials of

a new drug therapy), but in behavioral interventions, it is impossible to blind participants to treatment group (e.g., participants will know if they are in an exercise intervention group or not). Different tools will also be required based on the design of studies included in your review (e.g., the Risk of Bias in Non-Randomized Studies of Interventions, ROBINS-I tool (Sterne et al. 2016), and the Cochrane Collaboration's tool for assessing risk of bias in randomized trials (Higgins et al. 2011) are specifically designed to assess study quality of nonrandomized and randomized trials, respectively). Guidelines also exist for critical appraisal and quality publishing of qualitative research (Barbour 2001; Tong et al. 2007, 2016; Hannes et al. 2010; see also ► Chap. 59, "Critical Appraisal of Quantitative Research"). Systematic reviews may not necessarily be undertaken to evaluate effectiveness, but rather explore areas of process; therefore, other frameworks may be useful in assessing study quality (e.g., a review exploring implementation of interventions may use the RE-AIM framework, such as in a systematic review of physical activity interventions in practice for adults with type 2 diabetes (Matthews et al. 2014)).

10.4 When Risk of Bias Measurement May Need to Be More Flexible

There are some cases where rigid risk of bias tools can be too strict and result in down-rating of evidence from particular types of studies, such as natural experiments (Humphreys et al. 2017) and "real-world" community-based interventions. For example, in the case of community-based interventions, flexibility in delivery of interventions may be necessary to suit a particular site compared to another (e.g., what might work in one school may not work in another school due to differences in structures in place at each location). To ensure success, there may need to be some flexibility in how an intervention is delivered and strict measures of intervention fidelity will rate such studies including flexibility as low quality. In this instance, it may be appropriate to adjust an existing risk of bias tool or create an appropriate indicator of quality applicable to this type of study, bearing in mind, as mentioned earlier, that the validity of tools will be affected if they are adjusted. With natural experiments, researchers are not in control of the intervention itself and steps such as blinding and allocation concealment may therefore be impossible (Humphreys et al. 2017). It is, therefore, recommended that authors interpret the ratings from risk of bias tools cautiously.

11 Meta Analyses

11.1 What Is Meta-analysis?

A meta-analysis is when similar outcome data are pooled statistically from across more than one study in an attempt to provide a more precise, larger, effect estimate than relying on the findings of a single study. The benefit of using such an analysis is

that a single study may report nonsignificant findings, but when data are pooled across several studies, statistical power to detect small effects is increased and overall significant effects may be identified. Therefore, there is lower probability of missing small effects than if exploring one or only a small number of studies. Subanalyses can also be undertaken to explore heterogeneity and variability in study results in more depth. For example, it might be of interest to explore differences in effect sizes based on total intervention length or the intensity of an intervention (frequency of delivery per week and individual session duration), such as in a review of physical activity and sedentary behavior interventions in young people with type 1 diabetes (MacMillan et al. 2014). Subanalyses can also be useful as sensitivity analyses by exploring differences in findings when data are analyzed based on study quality (e.g., comparing effect sizes in studies with low or high overall risk of bias ratings).

A meta-analysis involves calculating the effect size for individual studies, by utilizing data such as mean and standard deviation (to calculate the standardized mean difference), correlation coefficients, and risk or odds ratios for each group, and then calculating an overall summary effect size by pooling effect size data from across studies in the review. Calculations may be necessary to transform data into a common metric when the same type of data is not consistently reported across studies. By using standardized outcome data, if the same outcome has been measured in different ways (e.g., different questionnaires or scales are used to measure an outcome), these data can then be pooled. In some instances, it may not be appropriate to combine data on a particular outcome. For example, consider physical activity. There are many types (e.g., aerobic activities, muscular strength activities, flexibility), dimensions (e.g., frequency of sessions/activities, intensity, duration of sessions/activities), and resulting outcomes that could be measured and reported in an intervention study (e.g., step counts per day, maximal oxygen consumption, one repetition maximum during a deadlift, upper body flexibility). Conceptually and methodologically, it would not make sense to pool data for some of these outcomes together (e.g., step counts are very different to upper body flexibility). Therefore, the researcher needs to exercise judgment on what makes conceptual and methodological sense to include in a meta-analysis.

Homogeneity of outcome data should be explored to guide the type of model to use in a meta-analysis. Chi-square tests can be used to statistically explore homogeneity. If there is no heterogeneity across the results from studies (other than that from sampling), then a fixed effects model should be used to combine effect sizes. If heterogeneity is present, then a random effects model should be utilized.

Forest plots can be used to graphically display effect sizes across studies in a meta-analysis. An example of a forest plot produced in Cochrane RevMan Software is provided in Fig. 2.

Data for each study included in the meta-analysis are included alongside a square to indicate the effect size and a confidence interval (a line) to display the level of uncertainty around that effect (in this case in a random-effects model). The overall effect size for pooled data is shown by the diamond displayed underneath the squares for each study (in the above example the overall effect size is -2.21

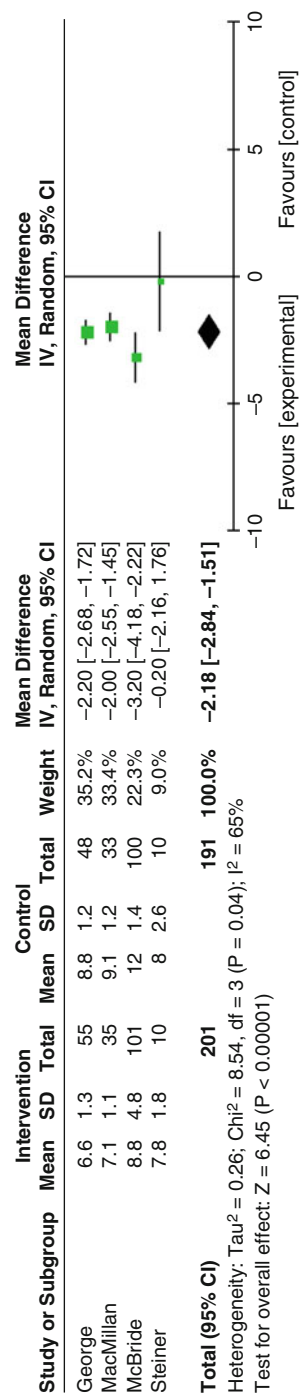
(95% CI, -2.84 to -1.59)). In Fig. 2, because the confidence interval for the overall effect does not cross the line of no effect, this indicates that, overall, there is a significant effect in favor of the intervention. The test for homogeneity suggests that a random effects model was suitable because heterogeneity was significant, ($p = 0.040$, $I^2 = 63\%$).

Funnel plots can be used to assist in identifying the chances of publication bias and can also be created in software such as RevMan. Funnel plots are scatter plots of study sample size (as an indicator of study precision) against effect size. The underlying premise of a funnel plot is that as sample size increases, variation in effect sizes will decrease and, therefore, effect estimates are more precise, forming an inverted funnel shape. If effect sizes do not form a typical funnel shape, then this would suggest publication bias, and potentially other biases too. Publication bias is when studies finding negative results (nonsignificant effects) remain unpublished due to authors not submitting their work to journals, or journals not publishing such findings. Publication bias can lead to an overestimation of overall intervention effectiveness. To avoid publication bias, researchers can search for relevant articles in nonpeer reviewed sources, including searching through trial and other study registers, and include non-English language studies. Additionally, there are statistical methods that can be used to explore and adjust for publication bias, but these tests are low-powered.

12 Creating a Narrative and Interpreting Findings

Most reviews will incorporate either a mixed narrative synthesis with a meta-analysis or, where a meta-analysis is not appropriate, solely a narrative descriptive synthesis. A narrative synthesis is a useful way of qualitatively summarizing the results of a quantitative systematic review when the studies included in the review are sufficiently heterogeneous, such that a meta-analysis is not possible. As mentioned earlier, when the evidence base is broad and studies are diverse (in their designs, outcome measures, and populations), a narrative synthesis can be a more appropriate way of summarizing patterns in the data, and providing an overall picture (or story) of the results.

Where a meta-analysis usually follows a strict framework, a narrative synthesis can be more subjective, which can be a disadvantage. One way to conduct a narrative synthesis is to summarize patterns of information using the number of studies reporting particular trends. For example, you may report that 10 studies showed a beneficial effect of an intervention, whilst 4 studies reported detrimental results. However, this method does not take into account the methodological quality of the studies and may lead to an inaccurate representation of the overall results due to bias. An alternative method involves weighting higher quality studies that have a low risk of bias in a qualitative synthesis. This might involve including a separate paragraph synthesizing the high-quality studies, which can then be used to make recommendations (see Steiner et al. 2017 for an exemplar) or reporting the findings in the context of the risk of bias (see MacMillan et al. 2017 for an exemplar). The FORM

**Fig. 2** Example of a forest plot

framework is a guide for formulating and grading recommendations for clinical guidelines, and can be applied to structure narrative syntheses and recommendations in systematic reviews (Hillier et al. 2011). The FORM framework comprises five components:

1. *Evidence base*, which covers the quality and quantity of evidence
2. *Consistency* of results across studies
3. *Clinical impact* of the work on the target population
4. *Generalizability* of the findings to the research question being asked
5. *Applicability* of the pattern of results to the population

By applying the FORM framework to a narrative synthesis, it is possible to make a clear recommendation about the pattern of results from a systematic review (e.g., that the intervention should be adopted, or results are mixed and further research is required). (For more information on reporting quantitative research findings, see ► [Chap. 56, “Writing Quantitative Research Studies”](#)).

Similar to narrative syntheses, there is no consensus on one standardized method for undertaking a meta-synthesis of qualitative studies (Lucas et al. 2007), although several frameworks have been proposed (Dixon-Woods et al. 2006). For example, a thematic approach groups or clusters data into themes, where a textual narrative synthesis involves describing and summarizing the major aspects of the study (e.g., study characteristics, results, similarities and differences, and study quality) (Lucas et al. 2007). (For more information on conducting and reporting a meta-synthesis, see ► [Chap. 45, “Meta-Synthesis of Qualitative Research,”](#) and [Writing/Reporting Qualitative Research Studies](#)”).

13 Conclusion and Future Directions

To summarize, systematic reviews can provide high-level evidence to inform decision making in policy and practice, particularly when conducted rigorously. Systematic reviews synthesize evidence, both quantitatively and qualitatively, across several studies focused on the same research topic. The steps within a systematic review are the development of a protocol including a detailed search strategy, database searching to identify citations meeting review inclusion criteria, screening of titles and abstracts and then full articles against inclusion and exclusion criteria, assessment of study quality using a risk of bias tool, pooling of quantitative outcome data in a meta-analysis where relevant and possible, and summarizing and interpretation of findings across included studies narratively.

With the ever-increasing quantity of health and social research being published, and the drive for evidence-based practice, special attention should be paid to the reporting of literature summaries. Rigorously conducted systematic reviews are, therefore, a crucial approach to ensuring that future policy and practice are guided by the most recent, high- quality evidence available.

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Content Analysis: Using Critical Realism to Extend Its Utility

47

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Contents

1	Introduction	828
2	What Is Content Analysis?	828
3	Types of Content Analysis	829
4	Historical Overview of Content Analysis	830
5	The Philosophy of Critical Realism	832
6	The Roots of Critical Realism	833
7	Critical Realism as a Stance in Content Analysis	836
8	Example of the Use of Critical Realism	837
9	Conclusion and Future Directions	839
	References	840

Abstract

Content analysis (CA) has become one of the most common forms of data analysis, but it is often criticized for a lack of rigor and limited utility of its findings. We define CA and describe its general procedures and the three most frequently used forms of CA. Next, we review the history of CA leading up to its current popularity within diverse disciplines, including social science and healthcare disciplines. Its origins highlight concerns about researchers' motivations underlying their interpretations of communications. In response, improved transparency and the application of CA in understanding underlying connotation in communications have furthered its evolution. CA can now be located on a

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continuum representing depth of interpretation, from surface description of phenomena to the uncovering of deeper meanings. We explore how CA may be used to uncover deeper underlying meanings and answer questions concerning how social relations, in connection with their context, affect outcomes such as individual behavior. By investigating deeper meanings, researchers can explore the core of the phenomenon and posit explanations of why the phenomenon is as it is. Finally, we argue that adopting an explicit philosophical orientation for inquiry will improve rigor and enhance practical utility of findings. We examine the philosophical and theoretical position of critical realism with CA. We then provide an example to illustrate the use of critical realism and outline the position's key aspects to consider in future directions of CA.

Keywords

Content analysis · History · Qualitative description · Critical realism · Rigor · Qualitative research utility

1 Introduction

This chapter focuses on a comprehensive understanding of content analysis (CA) and the ways in which CA can be used to investigate phenomena. The chapter opens with a definition of CA and a description of its process and then examines different forms of CA that reflect a continuum from shallow to deep interpretation. We review CA's history up to its current popularity as an analytic method across a variety of disciplines. To enhance its potential, we propose that the use of critical realism in CA can extend interpretation beyond surface description to a deeper understanding of how and why a phenomenon occurs. This approach will be illustrated using data gathered from a meta-synthesis focused on identifying influences on decision-making concerning transitioning patients to end-of-life care in intensive care units.

2 What Is Content Analysis?

We adopt a broad definition of CA that is applicable to both qualitative and quantitative research in areas ranging from social psychology to healthcare. According to Hsieh and Shannon (2005), CA is the process in which a researcher interprets the meaning or usage of written or visual data. These interpretations are organized into categories or themes using everyday language (Sandelowski 2010). This technique can be used to answer superficial questions of perception of a phenomenon, such as *What is it?* But it can also address more critical questions concerning the phenomenon's meaning: *What is it about? How is it happening? Where is it happening?* or *What may be its consequences?* (Sandelowski 2000). Addressing questions of meaning provides a richer picture of the phenomenon. With answers to these questions, the researcher can compare the data to existing evidence on the phenomenon, which will further shape the researcher's initial interpretations (Hsieh and Shannon 2005).

CA uses a systematic set of analytical steps. First, researchers examine the data about the phenomenon of interest in small chunks or phrases with meaning. Researchers give each chunk of data a label, or code, that reflects its meaning. They compare and contrast coded chunks against each other and group similar chunks to form conceptual categories. These categories reflect meanings and inferences about different aspects of the phenomenon (Hsieh and Shannon 2005). The derived categories are then compared to theories about the phenomenon in existing literature from the same discipline or across disciplines. Finally, a summary of the findings and their implications for practice, education, and future research are presented (Hsieh and Shannon 2005).

The way in which researchers apply the analytical steps of CA depends on previous evidence and theories. If existing literature about the phenomenon is scarce or inconsistent, then researchers may use an inductive process, whereby findings are derived from the collected data and then combined to form broader conceptual meanings or general statements (Elo and Kyngäs 2008, p. 109). Alternatively, if researchers have a theory or conceptual framework in mind, they may apply a deductive process, whereby the existing theoretical constructs are compared to the data observed from a group of participants from a specific context; this process validates the credibility of the theory (Elo and Kyngäs 2008, p. 109).

In social inquiry, researchers use CA to achieve one of two main purposes: (a) to uncover how a phenomenon is socially arranged and how it implicitly or explicitly works or (b) to describe how participants explain their behavior, to generate a cumulative understanding of the phenomenon (Miles et al. 2014). However, the degree to which the analysis accomplishes this goal varies widely depending on the research aim and questions. The purposes of CA are diverse, and while this can create confusion in how it should be conducted, its flexibility makes it a valuable method with which to get at multiple realities (White and Marsh 2006).

3 Types of Content Analysis

The researchers' research purpose or research question determines the use of one of three approaches to CA: summative, directed, or conventional (Hsieh and Shannon 2005). These approaches differ substantively in the depth of interpretation they offer and, thus, can be distinguished along a continuum of interpretation from shallow description to multifaceted construction of the phenomenon's meaning, processes, and mechanisms. We provide a brief overview of each approach below.

The first approach is summative CA, which draws more from quantitative than qualitative techniques. The purpose is to explore the contextual use of certain words in the text (Hsieh and Shannon 2005, p. 1283). The analysis, often referred to as *manifest* interpretation because it focuses on readily apparent meaning, is conducted by counting the frequency of particular words or phrases used by speakers in specific contexts. Further identification of the contexts in which the key terms are used – for example, whether use of particular terms for the same concept differs between patients versus healthcare providers or across age groups – informs the usage of

these terms (Hsieh and Shannon 2005). These findings may be reported using descriptive statistics (e.g., proportions, means). In addition, additional interpretation may involve *latent* or underlying meanings of key words or phrases. The findings can offer basic insights into the range of meanings conveyed about the topic and its key messages (Hsieh and Shannon 2005).

The second approach is directed CA (Hsieh and Shannon 2005) or conceptual analysis (Wilson 2016). Its purpose is to add credibility to or conceptually extend a theoretical framework or theory (Hsieh and Shannon 2005, p. 1281). Initial codes and categorizations are derived from existing literature or a theoretical framework and applied deductively to code the data. Data that do not reflect the concepts within the a priori coding scheme are inductively assigned a new code through manifest or latent interpretations. Researchers, thus, report on categories that validate the theoretical framework but also on new concepts that further expand or refine the theoretical framework or phenomenon (Hsieh and Shannon 2005).

The third approach is conventional CA, which is a strictly descriptive approach using both manifest and latent inferences to understand a phenomenon. This is the most inductive type of CA and is used when limited research or theory exists about the phenomenon. Researchers assign codes to label key thoughts or ideas. Related codes are then grouped into meaningful categories, and initial categories help organize subsequent codes into meaningful clusters (Hsieh and Shannon 2005). This type of CA provides a much more comprehensive picture of the phenomenon, through new insights exclusively grounded in the data, than the other two types (Hsieh and Shannon 2005).

Next, we provide an overview of the history of CA, which originated from concerns about motivations underlying public communications but also motivations underlying people's interpretations of these communications. Improvements in transparency and the application of CA to understanding underlying meanings and motivations in communications have led to progress in the evolution of CA, and it has become a popular methodology across disciplines. Despite such progress, criticism is still frequently leveled at CA as an atheoretical and often poorly conducted methodology (Sandelowski 2010, pp. 79–80).

4 Historical Overview of Content Analysis

CA originated in the eighteenth century in Sweden, from political debate about meaning in journalistic writing that went beyond straight reporting of facts. Beginning early in the twentieth century, the wide circulation of newspapers led to the first kind of CA, known as quantitative newspaper analysis. Journalists analyzed how the news was reported to support their arguments and provided commentary on public sentiment about an issue. It was then that Schools of Journalism studied how public sentiment could be quantified to reveal what was important to the public (Krippendorff 2013).

However, as journalists became adept at reporting public sentiment, it became apparent that the analytical processes they used were not transparent, and people

began to question how representative journalistic commentaries were of the general population's opinions (Krippendorff 2013). Questions about the journalists' attitudes and biases arose, which others felt reflected hidden agendas, such as motives of profit. In response, psychologists investigated the psychological relation between newspapers and their readers to form a systematic assessment of biases in newspapers (Allport and Faden 1940). This was published in the *Public Opinion Quarterly*, in a document entitled *The Psychology of Newspapers: Five Tentative Laws* (Allport and Faden 1940). These "laws" were psychological principles aimed at assisting journalists in creating guidelines to provide fair and objective communication of information to readers (Allport and Faden 1940). This was the first attempt to create transparency and standards in how CA was conducted. However, social scientists continued to question the representativeness of findings in CAs, raising such issues as the following: How were constructs theoretically motivated? How were ideas operationally defined? How did stereotypes occur? What social values did news ideas represent? (Krippendorff 2013).

In 1941, CA came to be known as the systematic analysis of mass communications such as propaganda. In particular, analysis of propaganda during World War II led to the awareness that underlying meanings, or latent content, communicated motivations and political interests (George 1959). Indeed, analysis of speeches given by the Nazi propagandist Joseph Goebbels enabled the United States' Federal Communication Commission to predict major Nazi military and political campaigns (Krippendorff 2013). Thus, people began to realize how words not only informed but also emotionally aroused and led to predictable responses in individuals. Moreover, the understanding of legitimate meaning required more than quantitative analysis, such as counting the frequency of words, but also qualitative understanding of the context connected to communicators' motivations (Krippendorff 2013). Hence, a shift from quantitative to qualitative CA began to occur.

From the 1960s to 1990s, CA was taken up by various disciplines – sociology, psychology, political science, literature, anthropology, library and information studies, linguistics, medicine, and nursing, to name a few – for intensive studies of individuals in naturalistic settings (Elo and Kyngäs 2008). According to Miles et al. (2014), literature from these disciplines followed a trend from description of manifest content to include: (1) inferring a phenomenon's antecedent conditions, (2) identifying symbolic or latent meaning (Krippendorff 2013), and (3) predicting stable social patterns, such as behaviors and relationships, from in-depth knowledge of the phenomenon (Miles et al. 2014). During the 1990s, CA focused on how messages were communicated, such as in the use of figurative language or illustrations. From patterns in communications, researchers inferred communicators' motives and their effects on others (White and Marsh 2006). In this way, researchers using CA could explore the social world not only to understand what was being said but also to interpret the *how* and explain the *why* of social phenomena (White and Marsh 2006; Sandelowski 2010).

In 2000, Sandelowski energized healthcare researchers, particularly nurses, to consider the utility of CA as basic or fundamental to descriptive research. She asserted that, although it was less interpretive compared to other methods such

as interpretive description, CA was useful in that it could adopt any theoretical basis, such as the disciplinary or professional understanding of a phenomenon (Sandelowski 2010). In this way, CA was pragmatic and flexible and could enable inference of meaning in the most basic sense, “close to their data and to the surface of words and events” (Sandelowski 2000, p. 334), but also from experience, previous research, or existing theories (White and Marsh 2006). Further, CA allowed triangulation of qualitative and quantitative data to enhance validity and reliability of the social patterns being posited (White and Marsh 2006).

Overall, the current popularity of CA across disciplines is attributable to its capacity not only to produce findings close to the data as given but also to allow for inferences about how and why events or experiences happen. Thus, unlike earlier applications of CA that focused on the superficial purpose of quantifying qualitative data (e.g., frequency of words), current trends extend CA to examining context-dependent factors that may explain patterns of the phenomenon. This aligns with the original objectives for CA, to explain the nature of the social world, and how it came to be that way.

Although the methodology of CA continues to improve, the problem of representation of phenomena exists. What theoretical basis guides interpretation? How can researchers’ assumptions of the phenomenon be made more explicit? Even more worrisome is Sandelowski’s (2010) suggestion that interpretation could be reduced to “no interpretation” other than a “presentation of the facts of the case” (p. 79). Consequently, researchers may skim the surface in their interpretations and see phenomena as much less complex than it is.

We suggest that the lack of in-depth interpretation may be attributed to insufficient attention to adopting a theoretical position in CA. Representation of any phenomena requires a theoretical orientation to inquiry. A theoretical orientation positions researchers to know how to identify data that are relevant to the phenomenon of interest and to differentiate the relationships among different data elements. This is especially important when CA is used to understand complex social and healthcare problems, which requires looking at these particular phenomena from many different perspectives. To present one way to meet this goal and enhance the practical utility of descriptive research, we recommend conducting CA from the philosophical position of critical realism.

5 The Philosophy of Critical Realism

Critical realism is a philosophical theory that has been applied within social science, the systematic study of society and social relationships. The theory essentially suggests that, within both the natural and the social world, there are unobservable objects and events that have causal properties and, thus, cause observable events (Bhaskar 1998). Thus, the realist stance is that such entities may exist independent of our awareness of them. How reality comes to be understood epistemologically is relative to how we subjectively perceive it. Critical realists believe that perceptions of reality can change depending on unobservable subjective factors such as our

individual ideology and value commitments, mental state, and situation (Maxwell and Mittapalli 2010).

Critical realism in the social realm focuses on the qualitative nature of social objects and their relations with social outcomes of interest. In particular, it seeks to understand the underlying unobservable mechanisms that may or may not cause certain social outcomes (Elder-Vass 2010). Mechanisms refer to processes of interactions among social objects, structures, events, and so on that result in observed outcomes. They can be naturalistic or programmatic and work in different ways under different circumstances to generate diverse outcomes (Maxwell and Mittapalli 2010). The nature of mechanisms, as well as the objects from which they arise, is thought to be more dynamic in the social world than in the natural world (Elder-Vass 2010).

One significant application of critical realism has been to understand the influence of social structures, which refer to interactions within social groups (e.g., organizations, families) that possess historical or social properties or relations that govern the behavior of their members (Elder-Vass 2010; Cruickshank 2012). Thus, defined groups of people have causal properties (e.g., social norms), and these, as unobservable mechanisms, may condition individuals' thoughts and behaviors, though not necessarily determine them (Elder-Vass 2010; Cruickshank 2012). Knowledge production also occurs in a contextual process (Nairn 2012). Mechanisms in this case can induce normative or ritualistic ways of knowing and being in their local contexts. Social norms tend to be relatively stable for a period, so we can make assumptions about how they may influence events within that period and context (Elder-Vass 2010). An example is how we understand the way to behave in elevators: facing forward to the door. If someone stood facing the opposite way in an elevator, towards the back, this behavior would reflect resistance to conformity to social norms and elicit discomfort in others in the elevator. Thus, research questions applying critical realism attempt to uncover the underlying mechanisms that cause the phenomenon of interest to be as it is observed locally: *How, why, for whom, and under what circumstances does the phenomenon occur?*

6 The Roots of Critical Realism

The philosophy of critical realism originated in 1996 with Roy Bhaskar (b.1944-), a British philosopher who was concerned with the practice and philosophy of social theory. Since then, an increasing number of disciplines have applied critical realism to their research (Easton 2002).

Bhaskar (1998) viewed reality across three strata: (1) the empirical, (2) the actual, and (3) the real. The closest stratum to our experience is the empirical, referring to what we observe about the event and, most often, what we tell each other about the event. The actual is what objectively occurs, regardless of our perception of it and our knowledge of its occurrence; these are the events that are influenced by unobservable mechanisms. Finally, the real refers to the mechanisms that are

involved in causing changes in actual events and that are the focus of understanding in critical realism.

We illustrate this stratified reality using the following example. Suppose you see a man having difficulty breathing. He tells you that he started to feel light-headed and experienced pain in his chest while having lunch. He also tells you that he feels nauseous and is tasting vomit. In this example, what you observe (i.e., a man having shortness of breath) and what the man tells you about his symptoms, including what he was doing when these symptoms began, represent the empirical reality, or the storied construction of experience. The actual reality comprises the material things or events that actually exist or happen – in this case, likely some kind of medical event. Since no measureable medical data have been gathered from the man, such as an electrocardiogram, most individuals would not perceive this actual reality until such evidence is presented. Lastly, the real encompasses the possible causal mechanisms of the event, such as the man's unhealthy lifestyle habits or genetic predisposition to cardiac events. We cannot observe those mechanisms that contributed to the medical event because they are part of a complex process that operates outside of our awareness (Elder-Vass [2010](#)).

The three strata of reality described in critical realism are partially compatible with three existing philosophies and theoretical positions about knowledge: positivism, constructionism, and critical theory (Elder-Vass [2010](#)). However, critical realism also represents a movement away from all three philosophies and, thus, differs from them on significant elements. Each will be described below with reference to our medical-event example.

Positivism reflects the perspective of basic science, in that it views reality as objective and as that which is directly observable with the senses or with instruments; nothing that is not directly observable exists. Positivists focus on identifying consistent empirical relationships, typically through controlled experiments; such relationships are then assumed to represent law-like causal relationships. From this perspective, knowledge must be empirically derived (Philosophical Foundations [2006](#); see also ► [Chap. 9, "Positivism and Realism"](#)). However, critical realists oppose regularity in causation but rather suggest that patterns may be produced from unobservable mechanisms, such as mental states or group attributes (Maxwell and Mittapalli [2010](#)). In the above example, we suspect that the man is having a heart attack. We infer its presence from empirical data gathered (e.g., what the man is telling you). We could further determine if it is a heart attack by conducting empirical investigations, such as conducting electrocardiograms or blood tests. This type of knowledge reflects positivism. However, we could also infer underlying explanations that are not objectively knowable, such as whether he has a hidden motive to approach you. So, while critical realism supports material or measurable events as elements of the nature of knowledge (ontology), its fundamental difference to positivism lies in its epistemologically relativistic viewpoint (Maxwell and Mittapalli [2010](#)), which we discuss momentarily.

Constructivism is a philosophy of social science that opposes the positivist philosophy in that it views all reality as subjective. The perspective focuses on understanding and interpreting the meanings of human behavior and experience that

have developed socially and that are dependent on time and context. Like critical realists, constructivists take a skeptical attitude towards reality; they believe that reality is socially constructed rather than objectively observed and examine how narratives are constructed within a relational context (Cruickshank 2012). In understanding complex social situations, a philosophy of constructivism is helpful because, like critical realism, it espouses the epistemologically relativistic viewpoint that the reality of a situation is relative to the person's motives and social norms within the local context (Cruickshank 2012). Hence, the person and reality are intertwined, and what is happening is connected to the context (see also ► Chap. 7, "Social Constructionism"). In the example of the man's medical event, when a physician intervenes as we are helping the man, we may defer to the physician because we, as a society, agree that physicians have the knowledge and authority to best assess and treat medical events. This belief is socially constructed, and it influences our actions because the practice of medicine is sanctioned by the medical system. Further, social structures, such as the medical system, and social norms possess power because we repeatedly reinforce and reproduce norms. However, critical realism differs in that it posits that we are affected by our social environment but can act to resist or transform it. Thus, we are not fully determined by social conditioning, as constructivism at a macro-level suggests, but still possess some autonomy over our agency or actions (Elder-Vass 2010; Cruickshank 2012).

Critical theory seeks to analyze what is in the interests of society and the societal assumptions about what is normal (i.e., ideology and cultural norms) that exist independently of individuals (Kellner and Roderick 1981). The theory recognizes that meanings inherent in the language we use shape groups of people within a specific time, culture, and societal structure. In our medical example, when the physician intervenes, we tend to talk and behave in a way that acknowledges his/her authority, and the physician tends to accept this responsibility and act on it. This is because we have been socialized within our society to the role that physicians play and its significance, as well as to the appropriate ways to relate to each other in these roles (e.g., deferring medical decision-making to the physician's expertise). This type of knowledge is the focus of critical theory (see also ► Chap. 8, "Critical Theory: Epistemological Content and Method").

Within social inquiry, both critical realism and critical theory, we (1) try to understand naturally occurring behavioral patterns that are created by social structures and mechanisms and that promote change in social systems (Elder-Vass 2010), (2) believe that language has pre-existing origins and implicit meaning, and (3) consider the broader social consequences of processes such as language and social relations. Language possesses causative properties, and both critical realism and critical theory are concerned with how language reinforces social structures or triggers other social structures. Unlike critical theorists, critical realists assume that social structures and mechanisms change over time and contexts and that these changes can lead to different outcomes (Elder-Vass 2010). In addition, critical realists take into account how difficult it can be for changes to occur in the face of shifting social forces in those who are ingrained in their ways of being; critical theorists do not consider this issue (Elder-Vass 2010).

Our understanding of how mechanisms trigger social structures to change outcomes provides us with a fuller understanding of the structures themselves (Elder-Vass 2010). Sometimes, opposing forces can work persistently within a structure. For example, findings from a literature review exploring decision-making in intensive care units indicated that conditions supported both resistance to and initiation of palliative end-of-life care for patients with a high risk of mortality post-ICU (Leung et al. 2016). We discuss this study later to illustrate the use of critical realism.

7 Critical Realism as a Stance in Content Analysis

Researchers may use CA following critical realism if they are interested in understanding how emergent causal properties occur in a social situation. Of particular interest for critical realists is how different patterns within social structures facilitate or block changes or outcomes in a naturalistic system, with broad social consequences (Pawson et al. 2005; Elder-Vass 2010). In addition, critical realism allows for different types of data to be used in the same study because this perspective accepts multiple strata of reality – the empirical, the actual, and the real (Nairn 2012; Porter and O'Halloran 2012). Critical realism also does not center on specific texts or numbers but rather can utilize quantitative and qualitative data to produce a unified interpretation. It can, therefore be used when different research approaches are concurrently employed, as in mixed-methods studies (Maxwell and Mittapalli 2010).

Commonly, CA is applied in qualitative descriptive studies. Qualitative description is a distinctive qualitative methodology suitable for variants of CA (Sandelowski 2010). This is because qualitative description reflects a theoretical position, known as the factist perspective, that limits the degree of interpretation to addressing material or measurable constructs that have predictive power (Sandelowski 2010). However, we agree with Sandelowski (2010) when she states that qualitative description should not be viewed as a “fixed way of ordering the world of inquiry” (p. 80). Rather, the boundaries of what we believe about reality are permeable. This means that qualitative description does not need to remain static. It may act as a foundation from which to extend the degree of meaning in interpretation further along the interpretive continuum, from shallow to deep interpretation. We suggest that critical realism can provide much-needed flexibility in understanding other types of realities by permitting us to access different types of knowledge. Its flexibility in CA draws not only from manifest meaning but also from the latent meaning of the context of the situation (Mayan 2009). The key is to look for and explore “what is into, between, over, and beyond text” (Sandelowski 2010, p. 78).

In summary, we propose that qualitative descriptive research applying critical realism to direct CA provides several advantages in getting at causal explanations about phenomena. Critical realism allows researchers to (1) explore a phenomenon from multiple realities with data collected using different methods; (2) study emergent causal properties in open, naturalistic contexts; (3) investigate explanations of consequences and outcomes that occurred; (4) acknowledge the ways individuals can actively resist or defy social structures, such as by engaging in protests or avoiding

responses to requests; and (5) acknowledge opposing forces between individuals and societal structures (Elder-Vass 2010). We now turn to an example of the use of critical realism in CA.

8 Example of the Use of Critical Realism

To illustrate how researchers can use critical realism with methods of CA, we describe the methodology from a published paper, *Transitions to end-of-life care for patients with chronic critical illness: A meta-synthesis*, by the first author of this chapter (Leung et al. 2016). While a detailed account of the study can be found in the publication, we provide a brief background and synopsis of the purpose and methods of the study.

Despite the high rates of morbidity and mortality post-discharge from intensive care units (ICUs) in patients with chronic critical illness, palliation is often not augmented during their treatment (Camhi et al. 2009). We conducted a critical literature review with the following purpose: “to identify social structures that contribute to timely, context-dependent decisions for transitions from acute care to end-of-life care for patients with chronic critical illness, their families, or close friends, and/or healthcare providers in an ICU environment” (Leung et al. 2016, p. 729). This purpose fits the aim of a particular type of literature review called a metasynthesis, which involves a systematic process of critically evaluating studies with qualitative data from different contexts (see ► Chap. 45, “Meta-synthesis of Qualitative Research”). The aim of a metasynthesis is “to develop a better conceptual or theoretical understanding or a different perspective of the phenomenon” (Tong et al. 2012, p. 181). The conclusions highlight knowledge gaps and provide direction in developing future research and practice interventions about the phenomenon of interest (Tong et al. 2012).

Critical realism fits well with the study’s purpose because treatment decision-making near the end of life is a complex, context-dependent process. In particular, society’s death-denying culture forms a social structure. Competing with this structure are mechanisms that reinforce society’s value of health as a right, the belief that we ought to benefit from access to all service interventions when making decisions about our health, and the desire to die well at the end of life. These structures and mechanisms dominate ICU conversations, but there is little recognition of how they may affect the outcomes of treatment decision-making near the end of life (Boniatti et al. 2011).

Leung et al. (2016) utilized the principles of critical realism to guide analyses that moved from theory construction to theory refinement. The focus of the research questions was to describe specific mechanisms of healthcare providers’ end-of-life decision-making and initiation of decision-making discussions with patients and family members: (1) How were decisions made? (2) Who communicated decisions to patients and families, and how were decisions communicated? (3) What resources and strategies helped in decision-making? and (4) What problems were resolved or persisted during decision-making? The researchers searched the literature for

relevant qualitative and mixed-method studies. Inclusion criteria were as follows: studies, written in English, reporting on (1) adults with chronic critical illness, their families or close friends, and/or ICU healthcare providers, and (2) processes of decision-making on end-of-life care for patients with chronic critical illness (Leung et al. 2016, p. 730).

Leung et al. (2016) found five relevant qualitative articles reporting interview and observational data. After reviewing the articles for overall comprehension of the data, the authors grouped data with unique meaning and labeled them with descriptive codes. These codes captured both their manifest and latent meanings. Manifest codes reflected empirically based interpretations that remained close to the overt, literal meanings of the data, whereas latent codes reflected possible underlying mechanisms, such as behavioral dispositions, habits, and communication skills, connected to the ICU context in which they occurred (Leung et al. 2016).

To illustrate, we use a chunk of data from one of the reviewed papers, by Sinuff et al. (2009), that Leung et al. (2016) included in their metasynthesis. Sinuff et al. (2009, p. 155) reported the following:

The central theme of family members' experience with mechanical ventilation was "living with dying." Families felt perpetually challenged to understand the patient's state while ventilated: is my loved one alive or dead, recovering or dying? The ventilator symbolized efforts to keep the patient alive but simultaneously indicated the patient's proximity to death.

Sinuff et al. (2009, p. 155) presented a quote from one interview to support their interpretation: "It makes you think of death. . . If they take him off he's going to die. . . you're living with death."

Recall Bhaskar's (1998) three strata of reality, theorized as causal processes by which objects and social relations constituting social structures may or may not generate predictable consequences. Leung et al. (2016) conceptualized aspects of the families' experiences of a threat to mortality along each of the three strata of reality. The participant's statement, "It makes you think of death. . ." was considered representative of the empirical. The contiguous context, such as the *sporadic, unplanned, decision-making in response to the deteriorating state of patients on mechanical ventilation*, was representative of the actual. Finally, what emerged in Leung et al.'s (2016) analysis was evidence of an underlying mechanism, they labelled as a process of *questioning of patient's quality of life*, and *the healthcare providers' dispositions to collaborate with families*, when families struggled to understand the patient's condition. This was one important mechanism that was considered representative of the real. Thus, all three strata of reality were identified as present in the one chunk of data from Sinuff et al. (2009) (Fig. 1).

Leung et al. (2016) posited that structures, such as the culture of cure within the ICU, and mechanisms, such as healthcare providers' work to suppress resistance by patients and families' recognition of dying (e.g., when families were not allowed to see the patients struggling to breathe when they were turned), could *lock in place routinized work of life preservation*, a derived subtheme. On the other hand, healthcare providers' disposition to collaborate with patients and families to

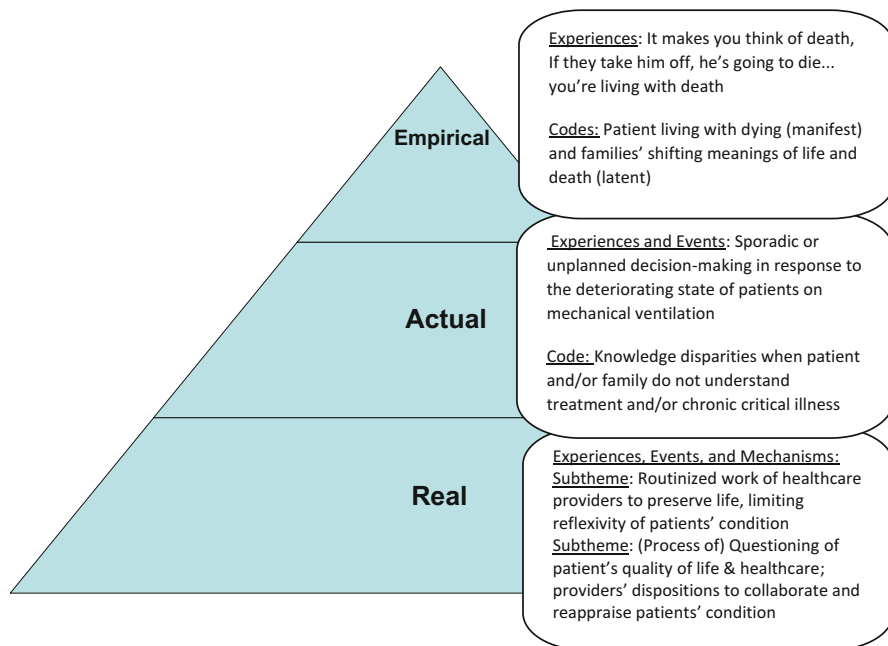


Fig. 1 Illustration of data in a stratified reality using critical realism

reappraise patients' condition, as well as families' questioning of patients' quality of life, could *open up access to augmenting end-of-life care*, another subtheme that conflicts with the preceding subtheme. Often, mechanisms worked together in the real strata, to trigger sporadic or unplanned decision-making and reveal the patient and/or families' knowledge disparities when it was clear that they did not understand treatment and/or the condition of chronic critical illness. This explanatory formula was prospectively tested against other data from selected studies. When the authors found it to be a concurrent pattern in all studies, they posited a main theme of *morally ambiguous expectations of ICU treatment*. This theme became the main process theorized to possess strong causal powers in social interactions among patients, families, and the healthcare providers. These social relations constituted emergent but transient social structures in the ICU. The theory was refined to improve the theoretical understanding of how patients with chronic critical illness did or did not transition from acute to end-of-life care in ICUs.

9 Conclusion and Future Directions

Content analysis (CA) has become the most common form of data analysis, despite criticisms about its lack of rigor and limited utility of its findings. The three most frequently used forms of CA and their capacity to represent interpretation along a

continuum lend to the appeal of CA: researchers may access surface description or deeper meanings of representation. We suggest for future directions that CA can posit explanations of why the phenomenon is as it is by applying critical realism to identify social structures and important mechanisms. Without the clarity of a theoretical orientation for inquiry, researchers using CA may not possess a clear understanding of what they are seeking to identify. This minimizes the symbolic and conceptual value of findings from CA.

We examined the philosophical and theoretical position and assumptions of critical realism as well suited to extending the instrumental effectiveness of CA. Future directions using critical realism with CA involve connecting social outcomes with processes that include both measures of observable facts and socially influenced factors (Maxwell and Mittapalli 2010). Critical realism places more weight on causal explanations than on the causal description of consistent relationships between phenomena that experimental research emphasizes (Elder-Vass 2010); the researcher applying critical realism emphasizes the processes that lead to the occurrence of certain phenomena under certain conditions. Hence, critical realism uncovers context-dependent mechanisms that provide causal explanations for phenomena (Maxwell and Mittapalli 2010).

We conclude by suggesting that researchers pay attention to diversity not as something extraneous but as something essential to understanding the processes of a phenomenon (Maxwell and Mittapalli 2010). Some social structures may emerge and others may not because of the diversity of individuals. Indeed, understanding particular cultural and social norms are critical to understanding when certain social outcomes or consequences may or may not emerge. As a result, CA using critical realism may generate more than one final, often contradictory, theme, and the validity of its findings may be constrained to local or similar situations, not to all situations (Elder-Vass 2010).

We do not suggest that CA using critical realism is the best approach; rather, critical realism provides flexibility for researchers to explore deeper latent meanings and mechanisms underlying the phenomenon and to posit explanations of how and why the phenomenon is as it is. This advantage can empower researchers conducting qualitative descriptive research to make data from less visible psychological, social, and cultural domains more tangible and findings more instrumentally useful, as is necessary in this age of evidence-based practice (Sandelowski 2004), and, indeed, essential to the evaluation of complex service interventions (Pawson et al. 2005).

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Thematic Analysis

48

Virginia Braun, Victoria Clarke, Nikki Hayfield, and Gareth Terry

Contents

1	Introduction	844
2	Thematic Analysis: A Brief History	844
3	Mapping the Terrain of Thematic Analysis: What Is a Theme?	845
4	Mapping the Terrain of Thematic Analysis: Different Schools of TA	847
5	Some Design Considerations for (Reflexive) Thematic Analysis	849
6	Six Phases of Reflexive Thematic Analysis	852
7	Conclusion and Future Directions	857
	References	858

Abstract

This chapter maps the terrain of thematic analysis (TA), a method for capturing patterns (“themes”) across qualitative datasets. We identify key concepts and different orientations and practices, illustrating why TA is often better understood as an umbrella term, used for sometimes quite different approaches, than a single qualitative analytic approach. Under the umbrella, three broad approaches can be identified: a “coding reliability” approach, a “codebook” approach, and a “reflexive” approach. These are often characterized by distinctive – sometimes radically

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different – conceptualizations of what a theme is, as well as methods for theme identification and development, and indeed coding. We then provide *practical* guidance on completing TA within our popular (reflexive) approach to TA, discussing each phase of the six-phase approach we have developed in relation to a project on men, rehabilitation, and embodiment. We conclude with a discussion of key concerns related to ensuring the TA you do – within whatever approach – is of the highest quality.

Keywords

Code · Codebook · Coding reliability · Epistemology · Latent · Reflexive thematic analysis · Semantic · Thematic map · Theme

1 Introduction

Thematic analysis (TA) is often misconceptualized as a single qualitative analytic approach. It is better understood as an umbrella term, designating sometimes quite different approaches aimed at identifying patterns (“themes”) across qualitative datasets. In this chapter, we first define key concepts and map the terrain of TA; we identify three distinct “schools” of TA, highlighting differences between these schools, particularly in relation to underlying philosophy and approach to data analysis. We then provide practical guidance on completing TA, focused on one of the most popular approaches – developed by two of the authors of this chapter (Braun and Clarke 2006, 2012, 2013).

2 Thematic Analysis: A Brief History

Philosopher of science Gerard Houlton has been credited with inventing TA in the 1970s, in his work on “themata” in scientific thought (Holton 1973; see also Joffe 2011). But the term was in use well before then: musicologists in the 1930s described the analysis of musical scores as TA (e.g., Kinsky and Strunk 1933); sociologists in the 1940s used the term to describe a method for analyzing mass propaganda (e.g., Lazarsfeld and Merton 1944); psychoanalysts in the 1950s used it to refer to techniques for analyzing the results of projective tests (e.g., Winder and Hersko 1958). The conceptualization of TA as an approach for analyzing patterns of meaning *may* reflect a methodological evolution from (quantitative) content analysis. The terms “TA” and “content analysis” have often been used interchangeably, and the hybrid term “thematic content analysis” is also common (e.g., Brewster et al. 2014). Regardless of its developmental origins, TA clearly has shared history with content analysis (see ► Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility”).

In the 1980s and 1990s – around the time there was a general explosion of interest in qualitative research – TA started to appear as a particular approach for analyzing *qualitative data* in the health and social sciences (e.g., Dapkus 1985; Aronson 1994). But it was the countless published papers that described some version of “themes emerging” from data, without reference to an established methodological approach to TA, that led us to describe TA as “a poorly demarcated and rarely acknowledged, yet widely used qualitative analytic method” (Braun and Clarke 2006, p. 77). That was 2006; just over a decade later, how things have changed! TA is now increasingly recognized as an approach to analysis in its own right (there is still some debate around this; see (Willig 2013)), and there are *many* different approaches to TA. The shared name “TA” obscures divergence, both in terms of procedures, and, more importantly, in underlying philosophy and the conceptualization of key elements of the method (e.g., a theme, a code, or coding). It is not uncommon to see researchers cite sources on, and sometimes follow procedures for, approaches to TA that do not align, conceptually or in practice. Not grasping these distinctions can result in published papers where the approach to TA used is unclear, procedures and assumptions are misattributed or mixed up, and underlying conceptual clashes between different approaches are not recognized. This does a disservice to TA. Avoiding such errors requires understanding of the conceptual and procedural differences within the terrain of TA. To aid clarity, we will define some key concepts in TA and consider the distinctive features of three “schools” of TA – which we refer to as “coding reliability,” “codebook,” and “reflexive TA.”

3 Mapping the Terrain of Thematic Analysis: What Is a Theme?

First up, it is vital to understand how “a theme” is conceptualized, as there are two competing ideas in TA research: domain summaries versus shared meaning-based patterns. We – and many others – view themes as reflecting a *pattern* of shared meaning, organized around a core concept or idea, a central organizing concept (see Braun et al. 2014). In this conceptualization, themes capture the essence and spread of meaning; they unite data that might otherwise appear disparate, or meaning that occurs in multiple and varied contexts; they (often) explain large portions of a dataset; they are often abstract entities or ideas, capturing implicit ideas “beneath the surface” of the data, but can also capture more explicit and concrete meaning; and they are built from smaller meaning units (codes) (DeSantis and Ugarriza 2000). An example of this type of theme comes from our research on meaning around male body hair (Terry and Braun 2016). A theme “men’s hair as natural” captured the way body hair was often described as natural for men and “a dominant expression of masculine embodiment” (p. 17). As well as reporting participants’ overt statements about the naturalness of male body hair (a “surface” level of meaning) – the theme

explored more nuanced manifestations of this idea – gendered assumptions that men *should* be hairy and women hairless and that men’s embodiment is biological (natural) while women’s is socially produced (worked upon), constructions which were naturalized and essentialized in the dataset.

In contrast to our conceptualization, a theme in a “domain summary” conceptualization *summarizes* what participants said in relation to a topic or issue, typically at the *semantic* or surface level of meaning, and usually reports multiple or even contradictory meaning-content. The (“theme”) issues are often based around data collection tools, such as responses to a particular interview question. Take the first theme in Roditis and Felsher’s (2015) research on adolescents’ perceptions of the risks and benefits of conventional cigarettes, e-cigarettes, and marijuana. The title – “perceived risks and benefits of conventional cigarettes compared to marijuana” – indicates a theme-as-domain-summary conceptualization, not least because it combines risks *and* benefits. And indeed, that is what is reported. Overview-type statements – “Youth either stated there was nothing good about using conventional cigarettes or stated that using cigarettes could help someone relax. Students easily recited a long list of negative consequences related to conventional cigarette use such as . . .” (p. 182) – highlight that the theme is a summary of youth perceptions in relation to a particular topic area.

Although some see domain summaries as a meaningful and useful conceptualization of a theme, others (e.g., Sandelowski and Leeman 2012; Connelly and Peltzer 2016) characterize them as at best underdeveloped or not fully realized themes and, at worst, misconceptualized. Some TA reports *do* read as if the analysis is only partly developed. For example, in Weatherhead and Daiches’s (2010) paper on Muslim views on mental health and psychotherapy, the seven themes – “causes,” “problem management,” “relevance of services,” “barriers,” “service delivery,” “therapy content,” and “therapist characteristics” – were effectively domain summaries. Discussing this paper in class, one of our students evocatively dubbed them “bucket themes”: you collect all the information gathered about X in one place, without considering shared meaning or difference. The theme “causes,” for example, described participants’ attributions for their mental health problems – explanations as diverse as reactions to life events and secular or religious notions that “life is a test.” Yet Weatherhead and Daiches’ discussion explored the “continued interweaving of religious and secular influences in participants’ account of mental distress and well-being” (p. 85), hinting at the potential for themes as shared-meanings, where the analysis is developed further and deeper. A domain-summary approach risks conceptualizing TA as simply a data reduction activity, where the purpose of analysis is to succinctly summarize the diversity of responses across the scope of a project. However, this *can* sometimes simply be an issue of ensuring shared-meaning themes are well-named (see Braun and Clarke 2013); we recommend avoiding one-word theme names to avoid this.

Approaches to TA also vary on whether themes are conceptualized as analytic *inputs* – patterns identified and developed at the *start* of the analytic process (usually following some data familiarization) which guide the data coding process – or as analytic *outputs*, patterns identified and developed *later* in the analytic process,

building on, and representing the *outcome* of, coding. To some extent, these conceptualizations align with the two different ideas about what a theme is.

4 Mapping the Terrain of Thematic Analysis: Different Schools of TA

We refer to *schools* of TA when we describe three broad “types” of TA, because there is not just *one* approach associated with each type. The names we use for the schools – coding reliability, codebook, and reflexive – emphasize the key distinctive element of each approach.

Coding reliability approaches – associated with authors like Boyatzis (1998), Guest et al. (2012), and Joffe (2011) – represent what we characterize as a *partially* qualitative approach to TA. Qualitative data are collected and analyzed using qualitative techniques of coding and theme development; the data are reported qualitatively as themes, typically illustrated by extracts of data. However, the underlying logic of these processes is firmly (post-)positivist, and some characterize these coding reliability approaches as “bridging the divide” between qualitative and quantitative methods. According to Boyatzis (1998, p. vii), (coding reliability) TA “is a translator of those speaking the language of qualitative analysis and those speaking the language of quantitative analysis.” Coding reliability TA researchers share values with quantitative researchers’ – for example, the importance of the reliability and replicability of observation – values at odds with (fully) qualitative paradigms.

In coding reliability TA, themes are often conceptualized as domain summaries (often derived from data collection questions), and as analytic inputs, as well as outputs – they *drive* the coding process and are the *output* of the coding process. The coding *process* is designed to prioritize “reliable” data coding, by which they mean identification of “accurate” codes/themes within data, usually based on agreement among multiple coders. Coding is guided by a codebook/coding frame, which typically contains a list of codes/themes – each has a label/name, a definition, information on how to identify the code/theme, a description of any exclusions or qualifications to identifying the code/theme, and data examples (Boyatzis 1998). This is designed to allow the researcher to categorize the data into (predetermined) themes. Despite a sometimes interchangeable use of the terms code and theme, *coding* is essentially conceptualized as a *process* (for identification of theme-relevant data and thus themes). Ideally, the codebook is applied to the data by more than one coder, each working independently; for some, the ideal coder has no prior experience with or knowledge of the topic of concern and comes to the coding process “cold.” After coding, the level of “agreement” between the coders is calculated (using Cohen’s kappa). A score of 0.80 and above is generally thought to signal accurate or reliable coding; lower scores are problematic, and lack of agreement needs to be resolved.

This coding approach can be understood as *consensus* coding – because it builds toward a singular, shared, and “correct” analysis of the data. The process has strong

echoes of “the scientific method” – the researcher develops a hypothesis (themes), tests these (searches for evidence of the themes using the codebook), is concerned about, and seeks to control for, “researcher bias” or “influence”, and, if the right procedures are followed, claims reliable and potentially replicable results. It reflects what Kidder and Fine (1987) described as “small q” qualitative research – qualitative research conceptualized as tools and techniques, not as a paradigm or underlying philosophy for research. We consequently characterize this school of TA as “partially” qualitative. To us, the idea that (such) TA can “bridge a qualitative-quantitative divide” is problematic, because it requires discarding what we see as central to good qualitative research practice – depth of engagement (“commitment and rigor” in (Yardley’s 2015) open-ended and flexible principles for qualitative research quality), an open and exploratory design and analytic process, and a prioritization of researcher subjectivity and reflexivity (Finlay and Gough 2003; Gough and Madill 2012). The *reflexive* school of TA emphasizes these elements.

Reflexive TA approaches include our (e.g., Braun and Clarke 2006) popular version of TA, as well as others (e.g., Langdrige 2004). In these, TA is conceptualized as a *fully* qualitative approach – with data collection and analysis techniques underpinned by a qualitative philosophy or paradigm – a “Big Q” approach (Kidder and Fine 1987). Although there is no widely agreed definition of a qualitative paradigm or, indeed, whether there is just one qualitative paradigm (Madill 2015), a qualitative orientation usually emphasizes meaning as contextual or situated, reality or *realities* as multiple, and researcher subjectivity as not just valid but a *resource* (Braun and Clarke 2013). We characterize this school as *reflexive* TA to emphasize the active role of the researcher in the knowledge production process.

In reflexive TA, themes are conceptualized as meaning-based patterns, evident in explicit (semantic) or conceptual (latent) ways, and as the *output* of coding – themes result *from* considerable analytic work on the part of the researcher to explore and develop an understanding of patterned meaning across the dataset. Coding is an organic and open iterative *process*; it is not “fixed” at the start of the process (e.g., through the use of a codebook or coding frame). Codes – the product of coding – can evolve throughout the coding process. An initial code might be “split” into two or more different codes, renamed, or combined with other codes. The aim of such changes during coding is to better capture the researcher’s developing conceptualization of the data. It is relatively easy to determine themes as domain summaries at the start of the analytic process; it is difficult to determine themes as conceptually founded patterns at the start, because it requires depth of (close and critical) engagement to move beyond the surface or obvious content of the data and to identify implicitly or unexpected unifying patterns of meaning. The aim of coding and theme development in reflexive TA is not to “accurately” summarize the data, nor to minimize the influence of researcher subjectivity on the analytic process, because neither is seen as possible nor indeed desirable. The aim is to provide a coherent and compelling *interpretation* of the data, grounded in the data. The researcher is a *storyteller*, actively engaged in interpreting data through the lens of their own cultural membership and social positionings, their theoretical assumptions

and ideological commitments, as well as their scholarly knowledge. This subjective, even political, take on research is very different to a positivist-empiricist model of the researcher. Many reflexive TA researchers do indeed have some kind of social justice motivation – be it “giving voice” to a socially marginalized group, or a group rarely allowed to speak or be heard in a particular context, or a more radical agenda of social critique or change.

We use the term *codebook TA* to describe a third “school” of TA – although many of these, which include framework (e.g., Ritchie and Spencer 1994; Ritchie and Lewis 2003; Smith and Firth 2011), template (King 2014; Brooks et al. 2015) and matrix analysis (Miles and Huberman 1994; Nadin and Cassell 2014), among others, do not use the actual term TA. This school of TA sits somewhere *between* “coding reliability” and “reflexive” TA, sharing the structured approach to coding with coding reliability TA (though often *without* the use of coding reliability measures) with the broadly qualitative underlying philosophy of reflexive TA. In codebook TA, some if not all themes are determined in advance of full analysis, and themes are typically conceptualized as domain summaries.

Some TA researchers, including template analysis proponents Brooks et al. (2015), have argued that researchers should not be precious about their way of working with TA. Although some friends and colleagues have (jokingly) suggested Virginia and Victoria are the “TA police,” issuing edicts about how TA should be done and rigorously punishing crimes against TA that do not follow our guidelines, we actually *somewhat* agree with Brooks et al.’s sentiment. Overall, what is important is that researchers use the approach to TA that is most appropriate for their research, they use it in a “knowing” way, they aim to be thoughtful in their data collection and analytic processes and practices, and they produce an overall coherent piece of work. Yet, we do *advocate* certain practices. From our perspective, the use of a structured codebook, determining themes in advance of analysis or following only data familiarization (using themes as analytic inputs) and conceptualizing themes as domain summaries, delimits the depth of engagement and flexibility central to *qualitative* research practice. There are, however, clear pragmatic advantages to codebook approaches – the coding framework allows teams of researchers to more easily work *together* on data analysis, facilitates a relatively quick analytic process, and provides some structure for qualitative novices. Taken out of a “consensus” and reliability framework, this has potential to produce rich nuanced analysis. But pragmatic factors should not (always) be the sole determinant of method.

5 Some Design Considerations for (Reflexive) Thematic Analysis

TA offers researchers great flexibility, meaning it can be used to do lots of the things that qualitative researchers are interested in. This flexibility stems from TA’s status as an analytic method, rather than a methodology, the latter referring to a theoretically-informed *framework* for research. Although the school of TA chosen

delimits a broad paradigm ([post]positivist or qualitative), beyond that there is scope to design and locate the method – and indeed, a requirement to do so, for reflexive TA.

Locating your overall theoretical and interpretative frameworks is important. Some treat TA as particularly compatible with phenomenological approaches (e.g., Joffe 2011; Guest et al. 2012), and it is indeed often used to describe or summarize participants' experiences, rather than to do more interpretative or conceptual work. But *why* TA should be limited to such an interpretative framework is unclear, and we think treating TA as a descriptive approach focused on experience underappreciates its flexibility and full potential. Indeed, it works well with many different interpretative frameworks, ranging from phenomenological ones to critical constructionist interrogations of meaning. And it, therefore, has the potential to answer different research questions. TA *can* address questions about, and be used to describe, the “lived experiences” of particular social groups (e.g., sex workers (Mellor and Lovell 2012), people with Parkinson's disease (Redmond et al. 2012), Asian migrants (Terry et al. 2011), adults with gay, lesbian, or bisexual parents (Titlestad and Pooley 2014)) or about particular aspects of their lives (e.g., the experience of freezing for people with Parkinson's disease (Redmond et al. 2012) or the health needs of street-based sex workers (Mellor and Lovell 2012)). It can also examine the “factors” that influence, underpin, or contextualize particular processes or phenomena (such as the factors that shape nurses' values in relation to compassionate care (McSherry et al. 2017)), identify views about particular phenomena (such as contested views about who is best placed to provide expertise in legal proceedings related to children's care (Hill et al. 2017)), or interrogate dominant patterns of meaning surrounding particular phenomena (such as the discourses underpinning the normalization of female genital cosmetic surgery on a cosmetic surgery website (Moran and Lee 2013)). Research questions for TA need to be aligned with the theoretical orientation of your TA.

TA also offers flexibility around data collection: interviews are common; focus groups are popular; diaries, visual methods, participatory methods, surveys, a wide range of secondary sources – such as online forums, blogs, websites, magazines, newspaper articles, and police reports – and many other methods have been used in TA research. As TA is generally a method for *across* dataset analysis (although it has been also used in case study research; e.g., Cedervall and Åberg 2010; Manago 2013), what is an adequate sample size? How many interviews should be conducted? How many participants should be recruited? How many hours of data should be recorded? These questions are perhaps some of the thorniest for qualitative research, although some concerns around sample size justification perhaps hark back to broader positivist-empiricist concerns with representation and generalizability, now connected to power analyses in statistical research.

Perhaps the most commonly used criterion for determining sample size in TA is “saturation” – such as claims that participants “were recruited until saturation was reached” (Gershgoren et al. 2016, p. 130; see also ► Chaps. 55, “Reporting of Qualitative Health Research,” and ► 58, “Appraisal of Qualitative Studies”). Here,

“saturation” typically refers to information redundancy, or collecting data until no new information is generated (there are other definitions), and some TA researchers have suggested saturation can be achieved in as few as 6–12 interviews (Guest et al. 2006; Ando et al. 2014) or 5 focus groups (Namey et al. 2016). Such papers are often cited to provide justification for relatively small sample sizes in TA research, but bold claims about saturation warrant interrogation. One problem with an information redundancy conceptualization is that it relies on an understanding of meaning as transparent and obvious *prior to* analysis. As TA (often) involves identifying new patterns of meaning, and this usually happens *after* data collection, *analysis* is necessary to judge whether the information generated by participants offers something new or not. Researchers who claim saturation, then, seem to rely on potentially superficial impressions made of data during data collection. This approach is more compatible with coding-reliability versions of TA. Where saturation has (attempted to be) operationalized, it is often within an implicit coding-reliability approach to TA (e.g., Guest et al. 2006). With such often surface-meaning-based and early-conceptualized analysis, it is easy to see how the appearance of “saturation” might be achieved in relatively few interviews. A recent paper suggested that if coding in TA moves beyond the surface level, larger samples are needed to achieve saturation (Hennink et al. 2016), and reported more conceptual codes achieved “saturation” with 16–24 interviews or not at all.

More problematic for using saturation as the rationale for sample size relates to the underlying philosophy of the research – in qualitative approaches that emphasize the partial, multiple, and contextual nature of meaning, and view knowledge as the actively *created* product of the interpretive efforts of a particular researcher (or researchers), combined with the dataset, the concept of saturation stops making sense (Malterud et al. 2016). We remain skeptical of the usefulness of the saturation concept, particularly when conceptualized as information redundancy, for determining sample size in TA research, and do not think it is useful for much “Big Q” TA. Researchers who use saturation need to do so from a position of theoretical “knowingness,” understanding the assumptions embedded in (their particular iteration of) this concept, and whether those are compatible with the underlying philosophy of their research.

What does this mean for sample sizes in TA research? Unfortunately, there are *no magic formulas* for determining sample size in TA research! We urge readers to be skeptical of anyone proffering simple formulas (e.g., Fugard and Potts 2015), as they always contain inbuilt assumptions (see Braun and Clarke 2016). Sample size is most often informed by various contextual and pragmatic considerations, some of which cannot be (wholly) determined in advance of data collection. Imagine a PhD student conducting TA research – their sample size could be informed by local “norms” around the appropriate scope of doctoral research, what is considered an acceptable sample size in journals the student hopes to publish their research in, and other such pragmatic “rules of thumb,” as well as more contextual considerations such as the breadth of their research question, the diversity within the population of study, and the amount and richness of data collected from each participant/case. Our pragmatic “rule of

thumb” is *at least* five or six interviews for a (*very*) small project, assuming the data are rich, the sample relatively homogenous, the research question focused, and the output an unpublished dissertation (for more “rules of thumb” advice on sample size, see Braun and Clarke 2013). It is also important to reflect on the sorts of claims made about themes developed, in light of the sample size.

6 Six Phases of Reflexive Thematic Analysis

Having discussed some conceptual and design issues, we now provide research-illustrated (see Box 1) discussion around the phases of *doing* (reflexive) TA, aligned to the “six-phase” approach we have developed, noting this as a reflexive and recursive, rather than strictly linear, process. For more practical step-by-step guidelines, see Braun and Clarke (2006, 2012, 2013) and Terry et al. (2017).

Box 1 The Men’s Embodiment in Rehabilitation Study

Despite three decades of calls for more research into men’s health, it continues to be underresearched, in general and in rehabilitation studies in Aotearoa/New Zealand. This project, theoretically located at the intersection of critical health psychology, critical rehabilitation studies, and critical disability studies, was designed to explore men’s experiences, practices, and sensemaking regarding male bodies undergoing rehabilitation for illness or impairment. Data were generated through one-to-one qualitative interviews with 20 men in various states of health and fitness, who had experienced recent (and extensive) rehabilitative treatment of some kind. Gareth Terry was the primary investigator and David Anstiss a postdoc researcher on the project. Rehabilitation was a new area of research focus for both.

Familiarization, which requires the researcher to shift focus from data generation (including transcription) to analysis, is fundamentally about appreciating the data *as* data. The process involves becoming “immersed” in the data and connecting with them in different ways: engaged, but also relaxed; making *casual* notes, but being thoughtful and curious about what you are reading. It is not about attaching formal labels – that comes later – but about looking for what is interesting about the data and what you notice about possibilities, connections (between participants, data, and existing literature), and quirks, which may add depth and nuance to your later coding. It can be one of the most enjoyable phases of the analytic process, and by providing a solid foundation of interrogating and thus “knowing” your data, it certainly makes the rest of the analysis *much* more enjoyable.

Practically, familiarization includes listening to audio data, watching video data, and/or reading and rereading textual data, “noticing” interesting features, and making notes about individual data items, as well as the whole dataset. These notes should be shaped by your research question(s), as well as broader questions about

what is going on in the data. For instance, in the men and embodiment project (Box 1), some key questions that Gareth and David asked of the data related to how “typical” understandings of men’s health might intersect with newly-experienced impairments and disabling environments – both social and physical. As researchers are new to the topic, familiarization was a crucial “entry point” into the data, providing them with an opportunity to closely read and thoroughly engage with the data, and giving room for reflexivity – asking questions of themselves and how they responded to the data. Consequently, much of the familiarization that occurred in the project involved making sense of ideas in the data that were new to them, which correspondingly made them aware of their own *abled* experiences and assumptions. Gareth and David engaged in the familiarization process concurrently, meeting several times to discuss their “noticings” and notes in detail. This process was not intended to produce any “consensus,” but rather to gain greater initial insight through sharing each other’s perspective on the data.

Generating codes moves to more detailed and systematic engagement with the data. We sometimes suggest familiarization could be done with a glass of wine, but coding needs coffee (or a good cup of tea). The coding phase in (our) TA is about focused attention, to systematically and rigorously make sense of data. If the familiarization phase could be considered a somewhat “loose” route into engaging with the data, the coding phase is about succinctly and systematically identifying meaning throughout the dataset. Data are organized around similar meanings and the content reduced into collated chunks of text. As a process, coding involves attaching pithy, clear labels (codes) to “chunks” of data, to help you organize the data around meaning-patterns (developed in later phases).

There are two broad orientations to coding: an *inductive* orientation, where the researcher starts the analytic process *from* the data, working “bottom-up” to identify meaning without importing ideas, and a *deductive* orientation, where the researcher approaches the data with various ideas, concepts, and theories, or even potential codes based on such, which are then explored and tagged within the dataset. In practice, any researcher *will* approach the data with preconceived ideas based on their existing knowledge and viewpoints. Coding inductively does not mean that we assume the researcher is a “blank state,” but, instead, that the starting point of the analysis is with the data, rather than existing concepts or theories (Terry et al. 2017).

Another consideration is the level at which “meaning” is identified and coded for – something partly informed by the epistemological approach of a project. *Semantic* codes stay at the “surface” of the data, capturing explicit meaning, close to participant language. *Latent* codes focus on a deeper, more *implicit* or conceptual level of meaning, sometimes quite abstracted from the explicit content of the data. The boundaries between these types of codes in practice are not always distinct; these codes represent ends of a continuum of ways of looking at data, rather than a binary. Initial coding for most TA projects is often semantic, and it can be hard to move beyond this level, to start to see the meaning *beyond* the obvious. As researchers become more experienced, or an analysis develops, latent-level meaning can be easier to “see” – but whether latent meaning is included can depend on the aims of the project.

Table 1 Example of coding, P1 (“Derek”) from the men’s embodiment and rehabilitation study

Data	Code
GT: So has that (pause) has that (pause) situation resolved itself a little bit	
P1: Nah I didn’t see my father at all (inbreath). I was really hopeless, lots of things happened that (pause) he was not supportive at all	“Harden up” mentality Relational breakdown with father Lack of affective recognition = unsupportive
GT: Yep	A long time to begin accepting
P1: He was a real cuppa concrete guy you know which is just not how it works (pause, inbreath); you know I was a lot worse then coz that was sort of two years in	Statute of limitations on acceptance Importance of supportive partner Importance of ACC support Financial means to get best treatment
GT: Yep	Recovery as relational
P1: Sort of accept it and move on you know. I was (pause) I’m not giving up (inbreath); there have been a few people that (pause) I mean I was fortunate my wife was very into research and stuff and she found (inbreath) my [private rehab clinic], and ACC paid for it; I think about 500 hours of rehab	

Transcription notation: *underline*₂ participant emphasis; (pause), pause in speech; (laughs), laughter from speaker

Gareth and David coded both semantically and latently, first working independently in the early part of this phase, then more collaboratively. Earlier familiarization discussions informed coding, but their emphasis was on generating a wide variety of codes to discuss and refine (see Table 1 for a brief example). Understanding that researchers look at data through their own lenses, and make interpretative choices throughout the analytic process (see Braun and Clarke 2016), they aimed to develop a diverse range of codes to build themes from, rather than trying to reach a consensus. Their practice demonstrates how more than one coder can work effectively with reflexive approaches to TA.

Constructing themes continues the active process of the previous phases. Themes are built, molded, and given meaning at the intersection of data, researcher experience and subjectivity, and research question(s). Because themes *do not emerge* fully-formed from the data, the process of constructing them is akin to processes of engineering or design. Prototypes (or *candidate themes*) are developed from the analytic work of the earlier phases, and “tested out” in relation to the research question/dataset overall. Knowing that not all candidate themes will necessarily survive this early development process is vital to not getting too attached. Good themes are those that tell a coherent, insightful story about the data in relation to the research question.

There are two key ways to develop codes into candidate themes. The first involves using codes as building blocks – similar codes are collated, together with their associated data, into coherent clusters of meaning that tell a story about a particular aspect of the dataset. This approach is most commonly how researchers move from codes to constructing (candidate) themes. However, sometimes a code may be “substantial” enough to be “promoted” to a theme – if it contains a central organizing idea that captures a *meaningful* pattern across the dataset, as well as different manifestations of that pattern. A common pitfall in (reflexive TA) theme development is identifying a feature of the data, rather than meaning-based patterns – features are somewhat akin to the idea of themes as domain summaries. For instance, men in the embodiment and rehabilitation project would often use humor to deflect questions about emotion and rehabilitation. This is potentially important information, but “humor” in and of itself is a *feature* of the dataset, not a meaning-based pattern. If the researchers could identify a conceptual meaning related to the use of humor, it might work as a theme, but alone, it does not.

Gareth and David again worked independently and collaboratively in the early stages of theme construction, meeting regularly to discuss candidate themes. Their meetings took the form of a kind of “theme off”: each presented their candidate themes, including preliminary theme names and definitions (discussed soon); they then “tussled” with each theme, and the collection of themes, to identify the most meaningful potential themes, the ones that collectively told the best story of the data. Thematic mapping – a process of visually exploring potential themes and subthemes, and connections between them (Braun and Clarke 2006) – was useful. Figure 1 maps the six candidate themes produced through this process, with all being relevant to the research question. Three of the initial themes Gareth and David constructed independently were similar enough to collapse into the single “bodies about more than roles and functions” theme – Gareth had identified a theme called “multiple embodiments”; David had two called “demanding embodiment” and “knowledge about bodies.” Their process demonstrates a way of working together, analytically, outside a consensus-building model.

The phases of *revising* and *defining themes* are particularly important, precisely because candidate themes *are* effectively prototypes. Sometimes they do not work! It can be difficult to “let go” of our early ideas, but holding too tightly to a candidate theme can potentially result in analytic “thinness” or conceptual overlap. The story being told about the data risks being diminished in richness, or conceptually confused, by inclusion of weak or overlapping themes. Having clear definitions of each theme – a paragraph delineating the theme’s boundaries and central organizing concept (for examples, see Terry et al. 2017) – helps clarify the essence and scope of each theme. Indeed, it was such descriptions of Gareth and David’s three candidate themes that highlighted their similarity and led to combination as a single theme (note that typically, not every facet survives this review process!).

Key to reviewing and defining is compiling all coded data for each of the candidate themes and reviewing them to ensure that the data relate to a central organizing concept; another stage of review involves checking the themes against the whole dataset. It is also important to develop a clear sense of how each theme

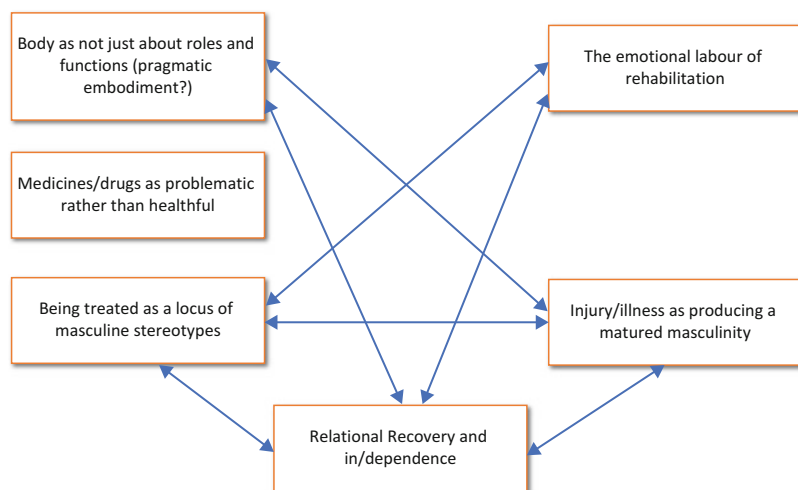


Fig. 1 Map of candidate themes from the men's embodiment and rehabilitation study

relates to the others. Thematic maps can be useful to visualize how the themes fit together and tell the *overall story* of your data – and to check that themes do not overlap. We often move from “early” maps for candidate themes, through to “final” maps when the revising phase is complete. For the men's embodiment project, it became clear when developing the (early) thematic map (Fig. 1), and comparing the definitions of each candidate theme, that some of the relationships between themes were stronger than others. The “resistance to medication” theme appeared quite independent (no connecting arrows); the other five themes all spoke to “relational outworking” of rehabilitation - how the men related to their bodies, and to others, and how they were related to *by* others. Thinking more deeply about the central organizing concept for each theme led Gareth and David to conclude that a notion of *recovery as relational* acted as an overarching theme (see Braun and Clarke 2013), an “umbrella” that contained three, related, themes: “bodies about more than roles and functions;” “being treated as a locus of masculine stereotypes;” and “the emotional labor of rehabilitation.” As analysis is a task of telling a compelling story about (aspects of) the data, they set aside one strong theme, “injury/illness producing a matured masculinity,” for future analysis oriented to *identity*. Through this process of revising themes, you aim for an in-depth and nuanced understanding of the central organizing concept and boundaries of each theme, including any subthemes (and overarching themes), and the overall theme story. Tables and similar tools can also facilitate in clearly identifying boundaries and structures of themes, in these phases.

Defining themes often leads to tighter/clearer theme names, which signal the scope and “core” of each theme. When you arrive at this point in the process, theme names will likely be somewhat makeshift – perhaps lengthy, or alternatively just one word – and only *provisionally* capture the content and scope of each theme. Final

theme names should succinctly cue the reader in to what they can expect to read about in the theme, *and* draw them into wanting to read the analysis!

The revising and defining phases seek to ensure that themes, *and* theme names, clearly, comprehensively *and* concisely capture what is meaningful about the data, related to the research question, getting you close to a “completed” analysis. The final phase, *producing the report*, is not, however, purely a writing-up exercise. Producing the report often serves as a final test of how well the themes work, individually in relation to the dataset, and overall. Revisiting the research question, your notes from the earlier phases of familiarization and coding, your lists of codes, and theme definitions can be useful to ensure that the final themes remain close to the data *and* answer the research question well (your research question can be “tweaked” for better fit at this point). The scholarly process of making connections to existing research and literature on the topic of interest, and weaving this in to the written results and discussion, may offer final moments of inspiration and a deeper insight into the analysis. Therefore, we urge researchers to view this phase as the final stage of analysis, and be open to making further revisions to the themes’ content, structure, and names. It may be that when you start to write your analytic narrative around the data extracts, you decide that some participant quotations do not as clearly demonstrate the point as other quotations do – your analytic claims may shift to reflect this. Or, as you write up your themes, you might notice that a change to the order in which they are presented would help with the flow of the story of your data, and so on. It can be useful to draw on our 15-point checklist (see Braun and Clarke 2006; Terry et al. 2017) to check the strength of your analysis and consistency across the report. We emphasize, again, that the epistemological position you have claimed will inform the terminology you use and the way you treat the data.

7 Conclusion and Future Directions

Despite TA providing an accessible method for (novice) qualitative researchers, there *are* plenty of potential traps and ways you can go wrong. Having read this chapter, you will be well-equipped to avoid many of these! In our view, good quality TA requires a degree of “theoretical knowingness” – an understanding of the philosophical basis of enquiry. This means, for instance, understanding the assumptions underpinning coding reliability or consensus coding practices, and understanding why these are *not* compatible with Big Q qualitative enquiry. Viewing theory as something that we *do*, rather than an abstract consideration divorced from the practical processes of conducting research, helps realize how essential this is. Imagine a supervisor telling a student “stop overthinking things and just get on with it.” Such advice suggests theory is *separate from* “getting on with it,” but theory is meshed into everything. We *do* theory all the time, in how we relate to participants, in our interviewing “style,” in how exactly we transcribe our interviews. . . All of these, and *many* other practical elements of research, reflect theoretical assumptions (implicitly made *or* actively chosen) about the nature of enquiry and what counts as meaningful knowledge.

Understanding theoretical bases also means you can avoid inconsistencies which mar too much published TA work. Too often we read research that contains statements like “following the procedures outlined by Braun and Clarke. . .” and then a description of analytic procedures that have little or no relation to those we outline. Sometimes coding reliability and reflexive approaches to TA are both cited, or the procedures combined, without any acknowledgment or justification of merging two philosophically divergent approaches. Sometimes researchers attribute analytic processes and concepts associated with grounded theory to TA (such as constant comparison, line-by-line coding, open coding, categories and subcategories, saturation; see Braun and Clarke 2013). Sometimes researchers claim domain summaries as conceptually founded patterns. . . Sometimes we really are left wondering whether the authors have actually *read* Braun and Clarke (2006)!

Is this us being picky, or does this really matter? Are we succumbing to methodolatry – the prioritizing of procedure above all else – something that “method-obsessed” psychologists, such as ourselves, are thought to be particularly vulnerable to? Does it matter if the end product (“the results” section) is good? We think it does matter! To us, these method(ological) “choices” – for example, combining consensus coding with Braun and Clarke (2006) – seem rarely to be made knowingly or reflexively. They seem instead to reflect a lack of understanding of, or caring about, the philosophical underpinnings of (Big Q) qualitative research or, perhaps, an (knowing or unknowing) acquiescence to the notion that (post)positivism is the only valid philosophy for research. Vitally, in a context in which there is not only much confusion about qualitative research, and its philosophical underpinnings, but much critique, these practices serve to create further confusion and even give the critiques some validity!

Furthermore, when published work is internally incoherent, or does not follow best- or even good-practice guidelines for any “school” of TA, this can be confusing, particularly for qualitatively inexperienced or student readers, who may assume publication is a guarantee of quality! We have often led a critical discussion of a published paper that ends with a student asking some variety of the question: “how does this stuff get published?” For the future of TA, all of us – scholars and researchers doing TA, reviewers, and editors – need to work hard to ensure consistency and quality in published TA.

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Narrative Analysis

49

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Contents

1	Introduction	862
2	What Is a Narrative?	864
3	Narrative Inquiry in Health and Social Sciences	865
4	Introduction to the Research Exemplars	866
4.1	Exploring the Experience of Emerging Adults with Cerebral Palsy	866
4.2	Exploring Family Life Following the Acquired Brain Injury of an Adolescent Child	867
5	Introduction to Two Approaches: Narrative Analysis and Analysis of Narratives	868
5.1	Narrative Cognition and Narrative Analysis	868
5.2	Paradigmatic Cognition and Analysis of Narratives	869
5.3	Complementary Use of Narrative and Paradigmatic Approaches to Narrative Inquiry	869
6	Narrative Analysis Techniques	871
7	Analysis of Narrative Techniques	872
7.1	Inductive Paradigmatic Analysis	873
7.2	Deductive Paradigmatic Analysis with a Theoretical Focus	874
8	Examples of the Outcomes of Narrative Analysis and Analysis of Narratives	875
9	Conclusion and Future Directions	877
	References	878

Abstract

Narrative inquiry methods have much to offer within health and social research. They have the capacity to reveal the complexity of human experience and to understand how people make sense of their lives within social, cultural, and

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861

historical contexts. There is no set approach to undertaking a narrative inquiry, and a number of scholars have offered interpretations of narrative inquiry approaches. Various combinations have also been employed successfully in the literature. There are, however, limited detailed accounts of the actual techniques and processes undertaken during the analysis phase of narrative inquiry. This can make it difficult for researchers to know where to start (and stop) when they come to do narrative analysis. This chapter describes in detail the practical steps that can be undertaken within narrative analysis. Drawing on the work of Polkinghorne (Int J Qual Stud Educ. 8(1):5–23, 1995), both narrative analysis and paradigmatic analysis of narrative techniques are explored, as they offer equally useful insights for different purposes. Narrative analysis procedures reveal the constructed story of an individual participant, while paradigmatic analysis of narratives uses both inductive and deductive means to identify common and contrasting themes between stories. These analysis methods can be used separately, or in combination, depending on the aims of the research. Details from narrative inquiries conducted by the authors to reveal the stories of emerging adults with cerebral palsy, and families of adolescents with acquired brain injury, are used throughout the chapter to provide practical examples of narrative analysis techniques.

Keywords

Narrative analysis · Social constructionism · Analysis procedures · Paradigmatic analysis of narratives · Story analyst · Storytellers · Narrative inquiry

1 Introduction

Narrative inquiry has been defined as a methodology “in which stories are used to describe human action” (Polkinghorne 1995, p. 5). Schwandt (2007) further explains that stories are central to all aspects of narrative inquiry. Narrative inquiry includes not only generating data in the form of stories but is also a means of analyzing stories about life experiences and a method of representing and reporting the findings of that analysis (Schwandt 2007). Narrative inquiry is grounded in the assumption that stories “constitute a fundamental form of human understanding, through which individuals make sense of themselves and of their lives” (Ylijoki 2001, p. 22). A life narrative allows people to interpret who they are and where their life is headed (Polkinghorne 1988). Even as children, stories are fundamental to learning to understand the world around us and our place within that social world. Stories continue to absorb us throughout our lives and become the “vehicle through which the reality of life is made manifest. . . we live by stories – both in the telling and the realising of the self” (Gergen 1994, p. 186). Through listening to stories, understanding is gained about the way people make meaning of their everyday lives within historical, social, and cultural contexts. Shared beliefs are understood, and values are conveyed (Polkinghorne 1988; Bruner 1990; Gergen 1994; Kramp 2004). Stories “assist humans to make life experiences meaningful. Stories preserve our memories,

prompt our reflections, connect us with our past and present, and assist us to envision our future” (Kramp 2004, p. 107).

Polkinghorne (1988) argues that adopting a narrative approach to research is critical to understanding the meaning of life events and many others agree (e.g., Bruner 1990; Gergen 1994; Mishler 1986, 1995; Reissman 1993, 1997; Ennals and Howie 2017). Bruner (1990) suggests that humans have an innate readiness or predisposition that leads to using the narrative form to organize experiences into stories that have a temporal sequence and an unfolding plot structure. Gergen (1994) adds that the tendency to tell stories is also culturally influenced. Family stories are told to conserve memory across generations and pass on family values and beliefs. In the home and school settings, young people are encouraged to tell their own stories about day-to-day life to evaluate the day’s events and their place in them (Gergen 1994). Narrative inquiry research is based on this same premise and assumes that by listening to people’s stories, understanding can be gained about the way they make meaning of their everyday lives within a broader social context (see also ► Chap. 24, “Narrative Research”).

This overarching view of the positive products of storytelling, based on a social constructionist perspective, is the foundation of narrative inquiry and narrative analysis. Narrative inquiry refers to an overall methodological approach to research, in a similar way that terms like phenomenology and ethnography refer to overarching qualitative research methodologies. According to Chase (2011, p. 421), narrative inquiry “revolves around an interest in life experiences as narrated by those who live them.” Within this broad agenda, however, narrative researchers’ interests, research processes, and outcomes differ significantly. There is a huge variety in what constitutes narrative inquiry. Some narrative researchers emphasize during data analysis the *whats* of narratives, that is, the content, plot, characters, and themes. Others focus more on the *hows* of narrative production, for example, the discourse used, semantics, structure, and form of language (Holstein and Gubrium 2012a). This chapter does not seek to provide an exhaustive account of all possible approaches to narrative inquiry; rather it introduces some key approaches with potential relevance to the health and social sciences. For interested readers, Chase (2011), Elliott (2005), Holstein and Gubrium (2012b), Mishler (1995), Reissman (2008), and Ennals and Howie (2017) all offer useful discussions of the broad varieties of narrative inquiry (see also ► Chap. 24, “Narrative Research”).

Narrative analysis refers to specific procedures undertaken during the data analysis stage of narrative inquiry. Narrative analysis is the primary focus of this chapter. To set the scene, the chapter commences with a brief discussion of narratives, narrative inquiry, and the complexity and variety of methods deemed within the literature to constitute narrative inquiry. The core of the chapter focuses on exploring data analysis procedures which can usefully be employed during narrative inquiries. The narrative analysis conducted by the authors in conducting two major narrative inquiries is outlined in detail, with examples from the research findings included to highlight the outcomes of narrative analysis. Finally, the chapter concludes with an overview of future directions in narrative analysis.

2 What Is a Narrative?

Narratives involve the integration of events and human actions into a goal-directed story which is organized temporally (Polkinghorne 1988, 1995). Narratives consider the influence of the past, present, and future and are presented within a specific place or sequences of places (Clandinin and Connelly 2000; Kramp 2004; Ennals and Howie 2017). Integration occurs when a thematic thread, or plot, is employed to allow individual events and happenings to take on a “narrative meaning” (Polkinghorne 1995, p. 5). Events and happenings are then understood in relation to their contribution and impact on a specific outcome (Polkinghorne 1995). A plot weaves together “a complex of events to make a single story” (Polkinghorne 1988, p. 19). This story, or narrative whole, reveals greater meaning than when individual events are viewed in isolation. An example is helpful to demonstrate this. The first author conducted a doctoral research project which aimed to understand the stories of emerging adults aged 18–25 years with cerebral palsy from their own perspective. The following life events were shared by a participant during an in-depth interview: “I left school in year 10,” “I started an apprenticeship,” and “I took some time off.” Viewed individually, these statements do not provide the complexity of understanding that is revealed through the narrative excerpt:

I left High School in Year 10 and started a hair dressing apprenticeship. That went down the gurgler. I hated it. Went to TAFE, started a course, hated that, it wasn't what I wanted. Then I had a bit of a mental health crisis, took some time off, went back and did [another course] at TAFE, which was brilliant. . . I didn't really know what I wanted to do. . . I kept going from one thing to another.

In accord with other authors in the area of narrative inquiry (e.g., Kramp 2004; Polkinghorne 1995; Reissman 2008; Liamputtong 2013; Ennals and Howie 2017), we believe that the terms story and narrative can be used interchangeably, and this convention is adopted throughout this chapter. It is important to note that some researchers in the field of narrative inquiry, particularly in social linguistics, hold a different view and define story and narrative as different but related concepts. Other authors previously held this view (e.g., Reissman 1993), but have more recently come to adopt “contemporary conventions” of using story and narrative interchangeably (Reissman 2008, p. 7).

Narratives are not only conceived differently by scholars, but they are also defined in various ways across different disciplines; there is no single meaning. For example, in social linguistics, narrative relates to a discrete unit of discourse, while in social history and anthropology, narrative can refer to an entire life story. Narrative in psychology and sociology generally refers to extended accounts of lives within a clear context. These accounts may develop over a single interview or multiple interviews. In the human sciences, the definition of narrative is even broader, referring to both the stories told by research participants during interviews and the interpretive accounts developed by the researcher as a result of data analysis (Reissman 2008). Reissman (2008, p. 6) labels this a “story about stories.” Reissman's broad definition of narrative has been adopted in this chapter.

3 Narrative Inquiry in Health and Social Sciences

The social constructivist underpinning of narrative inquiry can be particularly useful in understanding the lives of those whose experiences depart from “normative” expectations, such as those with disability or whose lives have taken an unexpected turn (Bruner 1990; Reissman 1993). For this reason, narrative inquiry has much to offer the health and social sciences. Narrative inquiry can be an approach that is most relevant to understanding the experiences, actions, motivations, and life journeys of people who are challenged by health, disability, trauma, change, adaptation, loss, or other significant life challenge. Narrative inquiry can contribute significantly to knowledge within the health and social sciences through its capacity to give voice to people whose voices have so often been discounted (Clandinin and Raymond 2006; Holloway 2007; Ennals and Howie 2017).

Narrative researchers, like other qualitative researchers, see their work as having potential to create positive change and address injustices. Many collect, present, and disseminate stories as a way of encouraging change (Chase 2011). For this reason, narrative inquiries are particularly relevant within the health and social sciences, where they have the potential to inform positive changes to practice, policy, education, and theory. Recommendations for change can be made on the basis of life experiences of people directly impacted by practices and policies. The potential of narrative inquiry to create positive social change has led to its popularity in research with marginalized and vulnerable groups (Liamputtong 2007). Chase highlights that “the urgency of speaking and being heard drives the ongoing collection and publication of narratives about many forms of social injustice” (Chase 2011, p. 428).

In the area of disability studies, for example, where our research has been focused, narrative inquiry puts the perspectives of people with disability, their families, and people who care for or work with them, “in the foreground of debates about care and constructions of impairment and disability” (Goodley and Tregaskis 2006, p. 632). Telling stories of disability has the potential to teach people with disability, and others, including service providers and policy-makers, about the complexity and diversity of experience. Smith and Sparkes (2008, p. 19) highlight that telling stories of disability has the capacity to “displace the tragedy story, challenge and resist social oppression.”

Outside of health and disability, narrative inquiry has potential to contribute greatly to wide ranging social research. Just some of the areas noted to use narrative as a methodological tool include studies of human behavior, criminology, family and relationships, sexuality, and the sociology of education (Elliott 2005). This is by no means an exhaustive list, and the potential of narrative inquiry is likely to be recognized in increasingly diverse areas, and by researchers with increasingly varied backgrounds, in the future.

The diversity of narrative inquiry also extends beyond the field of research to the types of data utilized in telling and analyzing stories. In-depth interviews remain a predominant data collection tool used by many narrative researchers, including the authors of this chapter (see ► Chap. 23, “Qualitative Interviewing”). However, the data used in the field of narrative inquiry has broadened significantly in recent years. The

addition of data including ethnographic observations, photographs, autobiographical writings, diaries, websites, and documents adds to the complexity and diversity of narrative inquiries now present within published literature (see ► Chaps. 26, “Ethnographic Method,” ► 65, “Understanding Health Through a Different Lens: Photovoice Method,” ► 30, “Autoethnography,” and ► 29, “Unobtrusive Methods”). Data gained through rapidly developing technological sources including social media, blogs, video logs, and podcasts is likely to continue adding to the complexity and diversity in the future (see ► Chap. 77, “Blogs in Social Research”).

Similarly, much variation exists in published narrative inquiries in relation to data analysis processes. Unlike other qualitative research methods, such as grounded theory, there is no standard analytical procedure for narrative inquiry research (Reissman 1993; Edwards 2016). It is impossible within this chapter to cover all possibilities. We will focus on the two distinct approaches to analysis in narrative inquiry detailed by Polkinghorne (1995). These are paradigmatic analysis of narrative data in the form of stories to produce categories, themes, or typologies and narrative analysis of data in the form of actions, events, and happenings to produce a narrative or explanatory story. As mentioned, these are not the only approaches to data analysis in narrative inquiry. Nor are we suggesting that they are superior to other approaches. Rather, this chapter aims to introduce the reader to two commonly used approaches, which individually, or in combination, may be useful for answering a broad range of research questions in the health and social sciences.

4 Introduction to the Research Exemplars

The following sections will utilize two key pieces of health research as exemplars to highlight techniques that can usefully be employed during narrative analysis. As mentioned, this chapter does not aim to be an authoritative source on the whole range of techniques that may constitute narrative analysis, as it is a hugely varied method open to significant interpretation. Rather, it aims to provide clear and replicable examples of those particular narrative analysis techniques and processes which have usefully been employed by the authors in health research and which may be useful to readers with similar worldviews and research aims. This section will briefly introduce the two research studies to set the context for the discussions that follow.

4.1 Exploring the Experience of Emerging Adults with Cerebral Palsy

Emerging adulthood has been identified as a unique developmental stage within developed countries (Arnett 2000). Generally associated with ages 18–25, emerging adulthood is seen as a time of identity exploration, instability, self-focus, a sense of feeling in-between, and possibilities. It is a time of profound change when people develop, review, and update their plan for the future (Arnett 2014). While emerging

adulthood is a time of significant change and transition for all young people, it may be even more challenging for young people with a lifelong disability such as cerebral palsy (CP). The first author's doctoral research aimed to address a significant gap in knowledge around the experiences of emerging adults with CP from their own perspective. It also aimed to reflect on the usefulness of both developmental (the theory of emerging adulthood) and disability (the International Classification of Functioning, Disability and Health (ICF) [World Health Organisation 2001]) frameworks in understanding the experience of emerging adults with CP. Specifically, this study aimed to answer the following research questions:

1. What are the stories of emerging adults aged 18–25 years with CP?
2. What key themes are evident within the stories of emerging adults aged 18–25 years with CP?
3. How do these stories and themes inform and/or extend the theory of emerging adulthood and the ICF, and are these two conceptual models useful in understanding the experiences of these young people?

Eighteen emerging adults with CP participated in multiple unstructured in-depth interviews, guided by Holstein and Gubrium's (1995) active interview approach. Active interviews allow for in-depth responses and do not dictate the course of the interview or use preset questions. Rather, they "loosely direct" the interview by setting certain parameters and introducing certain topics during the interview to elicit responses that are relevant to the aims of the research (Holstein and Gubrium 1995, p. 29). Active interviews invite participants to talk about their experiences narratively and are therefore highly relevant to narrative inquiries.

4.2 Exploring Family Life Following the Acquired Brain Injury of an Adolescent Child

In Australia, adolescents aged 15–19 years are the most likely group to sustain a brain injury (Australian Institute of Health and Welfare 2003). The purpose of the second author's doctoral research study was to explore family life after the acquired brain injury (ABI) of an adolescent child. The specific aim of the study was to understand how parental caregivers shape everyday family life during the first 2 years post-injury to accommodate the disrupted development of their adolescent child.

This investigation of family adaptation was underpinned by ecocultural theory (Gallimore et al. 1999). Ecocultural theory builds upon systems approaches to extend the understanding of how family ecology (e.g., income, housing, transportation, neighborhood) and family culture (e.g., family values, goals, needs) shape family life. Ecocultural theory applies a social constructivist perspective to family life. It recognizes the capacity of families to "organize, understand and give meaning to their everyday lives" and thus create a unique family "ecocultural niche" through the daily routine (Bernheimer et al. 1990, p. 223). Ecocultural theory holds that

parents construct daily life to meet the developmental needs of the children and family. Weisner (2002) refers to this process as the family's adaptive project.

The specific research questions addressed in this study were:

1. What is the adaptive project families engage in following the ABI of an adolescent child?
2. Do families engage in this process in different ways, and if so, how?
3. What implications do family ways of engaging in this adaptive project have for theory, practice, policy, education, and research?

Parents from 12 families where an adolescent aged 15–19 years had sustained a severe brain injury were interviewed using a narrative approach. Interviews took place over the first 2 years post-injury to capture the process of adaptation during the critical initial years of recovery (Khan et al. 2003).

The narrative analysis techniques utilized in the exemplar research studies will be explored in depth in the following sections.

5 Introduction to Two Approaches: Narrative Analysis and Analysis of Narratives

As previously mentioned, Polkinghorne (1995) made an important distinction between two types of narrative inquiry and, therefore, two types of narrative analysis. He based the two types on the two different, but complementary and equally valid, ways of understanding the world identified by Bruner (1985), narrative cognition and paradigmatic cognition. Discussion of how these two approaches can usefully be used, either separately or in combination, will be a focus of this chapter.

5.1 Narrative Cognition and Narrative Analysis

Narrative cognition is designed to understand the outcome of the interaction between a person's previous learning and experiences, their present situation, and their future goals and purposes. Narrative inquiry based on narrative cognition is labeled by Polkinghorne as *narrative analysis* (Polkinghorne 1995). Understanding is expressed by way of a story, with a plot that retains the complexity of the situation under exploration, and the emotions and motivations attached to it. Stories defined as using narrative cognition are complex accounts with a beginning, middle, and end, as distinct from a simple listing of a series of events. The plot, or point, of the story functions to enable researchers to select, from the multitude of data collected, those descriptions of happenings, events, and actions that relate to each other and are directly relevant to the story (Polkinghorne 1995). The result of narrative analysis is "an explanation that is retrospective, having linked past events together to account for how a final outcome might have come about" (Polkinghorne 1995, p. 16). The events are recounted in a time-ordered way that makes it clear how they contributed to the overall "point" (Gergen 1994, 1999). Researchers who conduct narrative

analysis have been termed *storytellers*, as the outcome of data analysis is itself a story (Smith and Sparkes 2009).

5.2 Paradigmatic Cognition and Analysis of Narratives

Paradigmatic cognition, in contrast, refers to methods that classify instances into categories and subcategories based on common attributes. Paradigmatic reasoning is common to both qualitative and quantitative research design; however, it is used in different ways. In quantitative research, the categories, or units of measurement, are usually identified before data collection. In qualitative research, conceptualization may take two forms. It includes the inductive discovery of categories or themes from within the data, and may also utilize deductive processes to explore how well data fits with predetermined concepts, usually those reflected in an existing theoretical framework or frameworks (Berg 2007; Polkinghorne 1995). Narrative inquiry based on paradigmatic cognition is referred to by Polkinghorne (1995) as *analysis of narratives*. It requires the collection of stories as data, followed by paradigmatic analysis that results in “descriptions of themes that hold across the stories” (Polkinghorne 1995, p. 12). Researchers who conduct analysis of narratives have been termed *story analysts*. They go beyond the collection and construction of narratives, which is the focus of *storytellers*. *Story analysts* further analyze stories in order to extrapolate categories, themes, or other theoretical propositions (Smith and Sparkes 2009).

The key benefit of analysis based on paradigmatic cognition is the ability to “bring order to experience by seeing individual things as belonging to a category” (Polkinghorne 1995, p. 10). It enables general knowledge about a collection of stories to be gained. It does however by necessity “underplay the unique and particular aspects of each story” (Polkinghorne 1995, p. 15), which are maintained in the alternative narrative analysis. In order to achieve the benefits of both approaches to narrative inquiry, and depending on the aims of the research, they can be utilized in combination.

5.3 Complementary Use of Narrative and Paradigmatic Approaches to Narrative Inquiry

Polkinghorne (1995) reinforced that both types of narrative inquiry can make important contributions to knowledge and produce valuable results. Within the literature, a range of different approaches are described, and various combinations of approaches have been successfully utilized. The different approaches are not mutually exclusive (Smith and Sparkes 2008). For example, Ylijoki (2001) interviewed 72 students and used a narrative analysis approach to construct four different core narratives around the experience of writing a master’s research thesis. McCance et al. (2001) identified common themes using paradigmatic analysis of narratives and also constructed six storied case studies using narrative analysis in

their research exploring caring in nursing practices. Cussen et al. (2012) used narrative analysis to construct individual stories for all of their adolescent participants and then derived common themes about aspirations for the future using paradigmatic analysis of narratives. Other researchers have also previously employed Polkinghorne's dual techniques successfully (e.g., Bailey and Jackson 2003; Kramp 2004; McCormack 2004). Bleakley (2005) goes as far as describing narrative analysis and analysis of narratives as being as complementary as a "lock and key: approaches of analysis and synthesis look different apart but constitute a unit together" (Bleakley 2005, p. 537).

This dual approach has been utilized by the authors in their research studies. Each type of analysis was employed for a different purpose. For example, in the first authors' research with emerging adults with CP, each participant's story was initially told individually, through the outcomes of narrative analysis. Each participant had an important story to tell, and the researcher wanted their story (as constructed by the researcher) to be included as a whole, not only parts of it in a fractured way. Narrative analysis provided the answer to the research question: what are the stories of emerging adults aged 18–25 years with CP?

Additionally, the research aimed to understand themes evident across stories and to understand how the stories inform the theory of emerging adulthood and the ICF. For this reason, a paradigmatic analysis of narratives approach was subsequently utilized to identify the common and contrasting themes present across stories. These themes were identified using both an inductive approach, directly from the data, and a deductive approach, whereby key concepts within the theory of emerging adulthood and the ICF were considered in relation to the data. Both processes will be outlined in the sections to follow.

Similarly, the second authors' research with families of adolescents with acquired brain injury initially presented a constructed story, developed through narrative analysis, describing each family's individual experience during the first 2 years post-injury. Analysis of narratives followed in order to explore and describe the adaptive family projects of the participating families. An initial common experience during the acute phase of recovery was identified and categorized thematically across all stories, along with three different adaptive family projects, or ways of living, during the post-acute phase of recovery over 2 years post-injury. Each adaptive family project was representative of several families' new way of living post-injury. Similar to the first exemplar, both inductive and deductive paradigmatic analysis of narratives techniques were employed, with the deductive analysis in this case associated with how families' adaptive projects related to key concepts from the guiding ecocultural theory.

The following section will explain in detail the processes for both narrative analysis and analysis of narratives used by the authors, to provide examples to guide the reader in planning their own data analysis procedures. For ease of explanation, procedures used during narrative analysis and analysis of narratives are described in this chapter separately. In reality, both forms of analysis can be utilized concurrently or at the very least considered throughout the analysis process. For example, while a researcher may focus initially on narrative

analysis, early identification of common and contrasting themes may occur during this process. These can be recorded and then further explored during more targeted analysis of narratives.

6 Narrative Analysis Techniques

The aim of narrative analysis is to construct a narrative which details a participant's experience in relation to the research question(s). Polkinghorne (1995) provides a useful description of criteria, first articulated by Dollard in 1935, which constructed narratives should aim to address. These criteria include:

- (a) Descriptions are included of the cultural and social context of the story.
- (b) Information is provided about the subject of the story (the research participant), for example, their age, developmental stage, and other information relevant to the aims of the research.
- (c) Explanations are included of the relationships between the participant and other significant people in their life.
- (d) The story concentrates on the goals, choices, interests, plans, purposes, and actions of the participant, on their meanings, and on their vision of the world.
- (e) Recognition is given to historical experiences and events that have influenced the participant's life story.
- (f) The story is bound by time; it has a beginning, middle, and end.
- (g) The narrative offers a meaningful explanation of the participant's experiences and actions, drawing together separate data elements in a credible and understandable way (Polkinghorne 1995).

Polkinghorne (1995) offers guidance around the actual process of constructing narratives. The researcher is encouraged to first consider the story's ending or outcome. This provides a lens through which parts of the data that are relevant to, or contribute to, that outcome can be identified. These data elements can then be arranged chronologically, and the connections between events and happenings can be articulated. Numerous direct quotes from the participant should be included to demonstrate key points using the voice of the participant. This ensures the narrative is grounded in data and authentic in tone. The overall aim of this process is to construct a narrative in which "the range of disconnected data elements are made to cohere in an interesting and explanatory way" (Polkinghorne 1995, p. 20). Developing narratives involves a recursive process of movement between the participant's data and the emerging story. Early attempts at writing the narrative should be tested against the data, and if events or actions are identified that contradict the emerging plot, further development and refinement is required (Polkinghorne 1995).

It is important to note the importance of the term "constructing narratives." The narratives discussed above are the researcher's construction of the participant's experiences. Narratives in research findings are not neutral depictions of the

participants' life stories. The construction is influenced by the researcher's own experiences, views, and priorities (Polkinghorne 1995). It is also influenced by the data produced through the dynamic and collaborative interactions between researcher and participants during in-depth interviews and by the narrative terrain of the research (Holstein and Gubrium 1995). The stories told through narrative analysis are not the same stories the participants would tell if they were asked to write their own story. They are unlikely to be the same stories another researcher may construct after undertaking similar research. But they offer an understandable and credible explanation of the participants' experiences, including many examples in their own voices. The stories constructed through narrative analysis should thus aim to "fit the data while at the same time bringing an order and meaningfulness that is not apparent in the data" (Polkinghorne 1995, p. 16).

7 Analysis of Narrative Techniques

In contrast to narrative analysis techniques described above, analysis of narratives is designed to compare and contrast various narratives, identify key themes, and/or explore narratives through a theoretical lens. While the analysis of narrative form of narrative inquiry is different to other types of qualitative research in that its data is in the form of stories, it is similar in many ways to other types of qualitative research in its analysis methods. Some researchers may find qualitative data analysis software helpful to facilitate the process of analysis of narratives, for example, NVivo, ATLAS, or Quirkos (see also ► Chap. 52, "Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses"). Interested readers are directed to Liamputtong (2013) and Serry and Liamputtong (2017) for a discussion of computer-assisted qualitative data analysis, its key functions, benefits, cautions, and considerations. However, we conducted our coding and analysis using more traditional, low-tech strategies during the exemplar research. These strategies will be outlined below.

As briefly outlined earlier in the chapter, analysis of narratives is based on a paradigmatic view of the world and is, therefore, designed to identify categories, themes, or typologies based on attributes common to stories (Polkinghorne 1995). There are two approaches to undertaking a paradigmatic analysis of narratives, inductive and deductive. Inductive analysis refers to deriving categories and themes directly from the data using such processes as constant comparison, made explicit initially by Glaser and Strauss (1967) and later by Strauss and Corbin (1990). Deductive analysis of narratives refers to analysis which is focused on exploring data for examples of theoretical concepts or pre-existing knowledge relevant to the research aims. Berg (2007) suggests that while inductive analysis allows the researcher to ground categories within the data, and therefore, most directly present the perceptions of participants, it is also reasonable that researchers should draw on their own experience with the study phenomena during analysis. Understandings gained from theoretical perspectives, existing scholarly literature and research undertaken in the field, can be drawn on and further clarified or explored through

deductive analysis methods (Berg 2007). Researchers can thus explore whether data fits with a predetermined theory or pre-existing knowledge in the field (Polkinghorne 1995). Techniques that can be usefully employed during both approaches will now be explored.

7.1 Inductive Paradigmatic Analysis

Polkinghorne (1995) describes the data analysis methods proposed for grounded theory by Glaser and Strauss (1967), and later Strauss and Corbin (1998), as being appropriate tools for inductive analysis of narratives. Two key grounded theory techniques are now introduced: asking questions and making comparisons (Strauss and Corbin 1998; Corbin and Strauss 2014). These analytical tools can be employed to assist the researcher to grasp the meaning of events, to sensitize the researcher to undiscovered properties and dimensions within the data, and to facilitate the linking of categories.

Asking questions enables a researcher to focus in on what the data is indicating, to understand structure and process, to identify connections between concepts, to stimulate thinking, and to increase sensitivity to what to look for in future data (Strauss and Corbin 1998; Corbin and Strauss 2014). Key questions that can be asked of the data include “Who? When? Why? Where? What? How? How much? With what results?” (Strauss and Corbin 1998, p. 89; Corbin and Strauss 2014). For example, “what is going on here?”, “why is this important?”, “how did this experience make them feel?”, and “how did they respond?”.

Making comparisons allows incidents within the data to be compared to other incidents in order to group them into categories according to similarities and differences (Strauss and Corbin 1998; Corbin and Strauss 2014). Grouped data is then coded by giving it a name or conceptual label that best summarizes the data (Strauss and Corbin 1990; Corbin and Strauss 2014). Questions the researcher can ask of the data to help guide comparisons include “did other participants have a similar experience?”, “did others report different experiences?”, and “what seems to be influencing the differences in experience?”.

Other paradigmatic qualitative data analysis techniques could also provide useful insights into techniques that could effectively be employed during analysis of narratives. For example, thematic analysis technique as described by Braun and Clarke (2006, 2013) is another example of an approach that can be used to derive themes inductively from data (see also ► Chap. 48, “Thematic Analysis”). Overcash (2003) provides a discussion of the relevance of thematic analysis in making sense of narrative data. Carson et al. (2017), in their study of the birth stories of young mothers, provide a useful example of a narrative analysis which utilizes thematic analysis procedures.

In the first author’s research with emerging adults with CP, inductive coding was initially recorded in the margins of hard copy transcripts, and various color markers were utilized to highlight related passages of text. For example, codes were identified during this process including bullying, transport and driving, mental health

problems, disclosure, and giving back. As analysis continued, the researcher developed knowledge of codes which had previously, or were commonly, appearing in the data; this “pool of concepts” was used to help guide further analysis (Strauss and Corbin 1998, p. 114; Corbin and Strauss 2014). Early codes were updated and developed as greater understanding of the nature of the concepts was gained (Strauss and Corbin 1998; Corbin and Strauss 2014). Codes and illustrative direct quotes from participants were recorded electronically within Word documents as data analysis progressed. Related codes were grouped into themes, and these were reviewed against new data for consistency and revised as necessary prior to the final compilation of results.

7.2 Deductive Paradigmatic Analysis with a Theoretical Focus

As introduced above, deductive analysis of narratives refers to analysis which is focused on exploring data to identify examples of theoretical concepts or pre-existing knowledge that is of relevance to the aims of the research (Polkinghorne 1995). This approach to paradigmatic analysis can sensitize the researcher to seeing concepts in the data that may not be evident without knowledge of relevant conceptual frameworks or theories. For example, the data can be examined to see whether key concepts that are widely understood and accepted in research literature or theory are evident in the unique experiences of participants. The theory is not used as a set of categories to fit the data into, but rather as a conceptual framework to examine the data in relation to, thus being able to possibly extend, refute, or support concepts and theories in relation to the participants’ experiences being investigated.

For example, in the first author’s research, deductive coding was completed concurrently with inductive coding and according to key concepts within the guiding theories. Data related to the five features of emerging adulthood (identity explorations, instability, self-focus, feeling in-between, and possibility) were recorded when they appeared in the narratives. Concepts related to the ICF were also coded: interpersonal interactions and relationships; community, social, and civic life; education, work, and economic life; attitudes; support; services and systems; and experiences of accessing the community. For example, where a participant was talking about how a particular experience had influenced the way he or she viewed him or herself, this was labeled “identity exploration.” When a participant spoke of the influence of others’ attitudes on their experiences, it was labeled “attitudes.”

In the second author’s narrative inquiry, ecocultural theory was used to guide deductive analysis of narratives. This involved coding data relevant to the adaptive family project post-adolescent ABI, in particular how parental primary caregivers shaped the daily routine to undertake this adaptive project. Weisner (2002) states that the adaptive family project can be analyzed in terms of its meaningfulness, ecological fit, and congruence. These three concepts are the summary dimensions of family life according to ecocultural theory, and therefore, coding was also undertaken to identify data related to these three theoretical concepts. The types of data included under the adaptive family project heading included how the daily routine was

structured and the aims that drove the construction of this way of life. Data pertaining to the meaning behind the construction of this project was then categorized under the heading of meaningfulness. The ecological fit category contained data relating to the resources families drew upon to continue with this routine and whether these resources were adequate to meet the aims of the adaptive family project. The congruence category contained data relating to how this adaptive project impacted on family members, for example, how parents juggled the demands of raising other children at the same time as helping their adolescent with ABI.

The following section will provide examples of the outcomes of narrative analysis and analysis of narratives. Depending on the aims of research, the structure of research results of narrative inquiries can vary significantly. Two examples are provided in detail from the authors' inquiries, and a range of alternatives are also highlighted from the literature, which may offer additional guidance and insight to the reader as they consider the most appropriate narrative inquiry approach to answer their research question or questions.

8 Examples of the Outcomes of Narrative Analysis and Analysis of Narratives

In the first author's research with emerging adults with CP, implementing a narrative analysis approach allowed the synthesis of participants' descriptions and stories into an individualized narrative of each emerging adult's experience, relevant to the research aims, which was organized by time. These constructed narratives were reflective of the data, but at the same time offered a new level of order and meaningfulness (Polkinghorne 1995). Each story included numerous direct quotes in the participants' own voices, offering a depth that is unequaled by other forms of data analysis. In the presentation of results, each of the 18 narratives was initially told as a stand-alone story. The outcome of inductive and deductive analysis of narratives was then presented. Fourteen themes were identified during analysis of narratives as important across the 18 participants' stories. These were presented and discussed, with multiple direct quotes from participants used to highlight the themes and to compare and contrast participant experiences. Examples of themes identified included: "The journey to find myself: Identity exploration," "Getting back on the road: resilient versus resigned," and "A bumpy road: Finding the right job."

In the second author's research, data analysis revealed an initial crisis period post-injury common to all parents. This was termed "willing survival and recovery" and detailed parents efforts to organize daily life to spend time at the hospital so they could focus on the survival of the adolescent. As recovery took place, and the adolescent returned home, parents assessed how the injury had altered their adolescent's development and how family life would need to change to accommodate the altered child. Three factors influenced parents' construction of daily life: the developmental discrepancy between their adolescent's abilities pre- and post-injury, the developmental pressure to resolve this discrepancy during the initial 2 years of recovery, and a sense

of developmental uncertainty about whether their adolescent would return to the previous developmental level given unknown recovery following ABI.

Three divergent ways of living emerged to manage this developmental uncertainty, discrepancy, and pressure. Some parents constructed “a rehabilitative life.” These parents worked hard to rehabilitate their child to facilitate the best recovery possible, altering family routines to concentrate on both formal and home-based rehabilitation. Others constructed a daily routine that focused around “the search for a settled life.” These families faced many disruptions due to their adolescents’ behavioral changes post-injury, and parents aimed to achieve a stable family routine. Another group of parents constructed “a cautious life.” The adolescents in these families had good recoveries post-injury and were able to gradually resume normal life. However, the trauma of the brain injury of their child led these parents to be more cautious, ensuring their child remained safe from harm during the recovery period.

In the presentation of results of this research, the initial common crisis was outlined, with multiple direct quotes from participants utilized to highlight the challenges of this crisis for families. The three divergent ways of living that emerged after the initial crisis period were then presented in different sections. These three ways of living were derived from the experiences of the 12 families, and each of the 12 families was categorized under the way of living that suited their new life post ABI. Initially, a constructed narrative for each participant within the group was presented, the result of narrative analysis. The overall adaptive family project of the group was then presented, the result of deductive analysis of narratives. Each adaptive family project was structured around the group’s experiences in relation to the ecocultural theory concepts of meaningfulness, ecological fit, and congruence. The meaning of everyday life, its ecological fit, and the congruence of the daily routine were differentiated within each adaptive family project with their own unique category names which reflected the dominant theme within the narrative data of this group. For example, within the “rehabilitative life” adaptive family project, meaningfulness was summed up and described by the category “hope and hard work toward a more normative life,” ecological fit was described under the category “rehabilitation resources: parents and professionals,” and congruence was described under the category “we all have to pull together ‘otherwise everything falls apart’.”

Within the literature, the reader will find a myriad of similar, and disparate, ways of presenting the findings of narrative analysis. Readers are encouraged to review the literature to locate exemplar research that is in line with their own research aims and worldview. In doing so, researchers can take guidance on approaches to narrative analysis that may be most appropriate to their own research. Just a few examples from the health and social sciences are presented here as a starting point for the reader’s further exploration.

Brown and Addington-Hall (2008) analyzed longitudinal narrative interviews with 13 people with motor neuron disease in order to explore how participants talked about living and coping with their illness. Four types of narrative storylines were identified within the stories of participants. The first was a “sustaining storyline,” about living life as well as possible and remaining engaged. The second was the “enduring storyline,” which concerned feelings of disempowerment that

resulted from living with a life-limiting illness. Survival was the essence of the third storyline, termed the “preserving storyline.” The final storyline concerned loss and fear of the future and was labeled the “fracturing storyline.” Storylines were not mutually exclusive, with more than one, or even all four, being present within some participant’s stories (Brown and Addington-Hall 2008).

In another valuable example, Davies et al. (2016) utilized narrative analysis in their study of older widows’ experiences of loneliness. Data analysis resulted in the identification of three themes: “experiencing the absence,” “loss of routine connection,” and “establishing new routines.” These themes were then reviewed and an overarching narrative, or collective story, of participants was identified:

The overarching narrative followed a trajectory, from the onset of loneliness associated with widowhood through a process of transition from marriage to widowhood. The loss of the spouse was experienced as a sense of absence that resulted in a loss of usual routines which had enabled a sense of connection with others. The participants had transitioned through establishing new routines thus creating new connections with others. (Davies et al. 2016, p. 535)

Lastly, Papathomas et al. (2015) explored the experiences of a 21-year-old elite triathlete with an eating disorder and the experiences of her parents. Open-ended, participant-led interviews were conducted over 1 year in order to provide a longitudinal perspective. Narrative analysis considered both the content and structure of the data and was guided by Frank’s (1995) typology of illness narratives. Analysis identified that the stories of the participants reflected a restitution narrative: “yesterday I was a healthy athlete, today I have an eating disorder, tomorrow I’ll be a healthy athlete again” (Papathomas et al. 2015, p. 317), with a turn to a quest narrative in the final interviews: “I’m just trying to make the most of it” (Papathomas et al. 2015, p. 322).

The examples presented within this section, both from our own research and published literature, provide the reader with a snapshot of the broad range of possible outcomes of narrative analysis and analysis of narratives. Many more possibilities are available to researchers who choose a narrative inquiry approach. This chapter concludes with a discussion of some of those possibilities and future directions for narrative analysis.

9 Conclusion and Future Directions

Stories and storytelling are inherent to human experience, help us make sense of our lives, and find meaning from events. Similarly, researchers can adopt narrative inquiry as an approach that is well suited to understanding people’s experiences related to a research phenomenon. In the health and social sciences, narrative inquiry is particularly relevant to understanding challenges people face and how they cope and adapt throughout their lives to significant turns in life: change to health, adaptation to or living with disability, trauma, nonnormative events, aging, and so

on. Narrative inquiry provides rich data from which researchers can better understand the details of individuals' lives and from that point understand the implications of research findings in relation to necessary changes to policy, practice, education, and theory.

The purpose of this chapter was to provide readers with a background briefing on narrative inquiry and illustrate key approaches to narrative analysis and analysis of narratives, using examples from research. This chapter did not aim to be, and does not pretend to be, an exhaustive or prescriptive source of information about narrative analysis. Instead, it aimed to provide practical guidance on those approaches the authors' have effectively utilized and which may be relevant for other research in the health and social sciences. In any narrative inquiry, the researcher needs to make choices about the best approach to data analysis and provide a clear rationale for these choices. There is, therefore, a need for researchers to articulate their worldview and the influence on the narrative analysis procedures they employ, as there is a huge variety in scope and actual data analysis techniques. Researchers are advised to carefully consider and justify the reasons guiding a decision to employ narrative analysis, analysis of narratives, a combination, or indeed other types of analysis not discussed in depth within this chapter.

Readers are also encouraged to share their own experiences and insights gained through conducting narrative inquiries. This will continue the important dialogue about narrative inquiry and narrative data analysis and support the further development and advancement of the methodology. In the words of Overcash (2003, p. 183), "the beauty of narrative methods is in the diversity and malleability of the methodology in capturing the human experience." Through sharing this diversity, including practical discussions of the *how* of data analysis, new ways of capturing and understanding human experience will evolve. We look forward to continued discussion, debate, and development of narrative inquiry and analysis.

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Critical Discourse/Discourse Analysis

50

Jane M. Ussher and Janette Perz

Contents

1	Introduction	882
2	Discourse Analysis and Discursive Psychology	882
3	Foucauldian Discourse Analysis	884
4	Synthesizing DA and FDA: A Combined Approach	886
5	Defining Discourse Analytic Methods	886
6	Analyzing Premenstrual Distress: A Feminist Discourse Analysis	887
6.1	Study Aim and Method	887
6.2	Women's Descriptions of Premenstrual Change	888
6.3	Premenstrual Change as Pathology: Woman as Victim or Monster	889
6.4	PMS as an Understandable Reaction: Facilitating Agency and Self-Care	892
7	Conclusion and Future Directions	893
	References	894

Abstract

Discourse analysis (DA) conceptualizes language as performative and productive, central to the construction of social reality and subjectivity. This chapter examines two identifiable, but overlapping, schools of DA, discursive psychology (DP) and Foucauldian discourse analysis (FDA). DP draws on the practices of ethnomethodology and conversations analysis and focuses on the *action orientation* of talk and text in social practice: what is the text *doing*, rather than what does the text mean, or “what is the text saying?” Analysis focuses on “interpretive repertoires” or “discourses”: sets of statements that reflect shared patterns of meaning. Foucauldian discourse analysis (FDA) originates within poststructuralist theory, influenced by the philosophical work of Michel Foucault. Within FDA, language is deemed to be constitutive of social life,

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881

making available certain subject positions, which influence and regulate subjectivity and experience – the way we think or feel, our sense of self, and the practices in which we engage. FDA is thus concerned with identifying discourses, the subject positions they open up (or disallow), and the implications of such positioning for subjectivity and social practice, rather than the form or structure of interaction within talk or text. Following discussion of a range of DP and FDA research studies, a detailed example of feminist FDA is provided, including steps of analysis, based on a study of women's accounts of PMS (premenstrual syndrome). It is concluded that there is no one correct method of DA, as multiple methods have been identified, and practitioners interpret and present analyses in a range of different ways.

Keywords

Foucauldian discourse analysis · Discursive psychology · Feminist discourse analysis · Premenstrual syndrome (PMS) · Discursive practices

1 Introduction

Discourse analysis (DA) is a form of qualitative analysis that followed the “turn to language” in the social sciences in the second half of the twentieth century. This “turn” marked a shift from the conceptualization of language as a reflection of thought or experience, to seeing language as both performative and productive, central to the construction of social reality and subjectivity. Discourse analysis has, therefore, always been more than a method – it is part of a broader critique of positivism-realism within social science disciplines (see Potter 2012; see also ► [Chap. 9, “Positivism and Realism”](#)).

DA evolved within a range of diverse disciplinary contexts, including literary criticism, linguistics, psychology, philosophy, and sociology. The influence of these disciplines shapes the nature and emphasis of the various strands of DA practiced today. For example, within linguistics, the focus is on fine grained examination of sentence structure and utterances; within cognitive psychology, attention is paid to the role of mental schemas and scripts in the comprehension of language (see Potter 2004). Within the Social Sciences, there is much rich and vigorous debate about the nature and function of discourse analysis, leading to a range of interpretations and developments (Hollway 1989; Wetherell 1998; Billig 2012; Parker 2012). This has crystallized into two identifiable, but overlapping, schools of thought, described as discursive psychology (DP) and Foucauldian discourse analysis (FDA). In this chapter, we will examine the theoretical and conceptual framework of both of these approaches, their commonalities and differences, and their applicability for the Health Social Sciences.

2 Discourse Analysis and Discursive Psychology

Initially described as “discourse analysis” (Potter and Wetherell 1987), and more recently as “discursive psychology” (DP) (Edwards and Potter 1992), this methodology is influenced by poststructuralist literary theory, as well as the sociology of

scientific knowledge (Potter 2012). DP draws on the practices of ethnomethodology and conversations analysis, and focuses on the *action orientation* of talk and text in social practice: what is the text *doing*, rather than what does the text mean, or “what is the text saying?” (Willig 2008, p. 98; see also ► Chaps. 16, “Ethnomethodology,” and ► 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis”). Analysis focuses on “interpretive repertoires” or “discourses”: sets of statements that reflect shared patterns of meaning. Topics recognized in mainstream health research, such as “attitudes,” “causal attribution,” “script,” and “knowledge,” are reframed as “discourse practices” (Edwards and Potter 2005, p. 241). Thus, for example, the study of attitudes is replaced by analysis of argumentative practices in discourse (Potter and Wetherell 1987).

Individuals conducting DP are concerned with the management of issues of “stake or interest” within talk (Potter 2004). For example, an individual may say “I’ve got nothing against gay people, but I don’t agree with gay marriage,” as a way of disclaiming a homophobic identity, then legitimate their position by appealing to a higher authority: “scientific research makes it clear that children need to be brought up by a man and a woman.” Within DP, attention is also paid to the *negotiation* of meaning within language and to the interaction between speakers in everyday situations. The *form* of language is also of interest, in order to examine “what people do” with language (Potter 2004, p. 203), and how they manage social interactions. Emphasis is thus placed on the rhetorical or argumentative nature of talk and texts, metaphors and analogies, extreme case examples, graphic descriptions, and consensus formulations (see Edwards and Potter 1992). The association of gay marriage with bestiality and polygamy within political and media debate in both the UK and Australia would provide ideal fodder for discursive analysis of extreme cases. Analysis is often focused on the often contradictory interpretative repertoires individuals draw on in their accounts (Wetherell 1998) and the rhetorical context within which such repertoires are deployed.

While many health social scientists conduct interviews as a means of analyzing discourse, naturally occurring talk is often the focus of analysis, as research questions center on how people account for themselves and interact in everyday life, with the intention of achieving personal objectives (Willig 2008). For example, Curl and Drew (2008) examined language use in phone calls to emergency services, and Rowe and colleagues (2003) investigated representations of “depression” in the print media in Australia. Lay accounts of health issues are a focus of attention, exemplified by studies men’s accounts of PMS in on-line chat rooms (King et al. 2014), and young women’s accounts of smoking (Triandafilidis et al. 2017a).

In a health or clinical context, interactions between patients and health professionals, therapists and clients, or lay people discussing health issues on the radio or TV, also provide appropriate material for investigation. For example, Rapley examined the social construction of intellectual disability, identifying the ways in which talk and text actively constitute the truths about being “mental” as well as “disabled” (Rapley 2004, p. 10), through the analysis of “official” texts, and the interactions of health professionals with people described as intellectually disabled. In a further study, McHoul and Rapley (2005) examined the transcript of a diagnostic session involving a young boy, his parents and a pediatrician, to contest the diagnosis of

attention deficit disorder (ADHD). In the extract below (p. 425), the mother's account of how she came to bring her son to see the pediatrician is analyzed:

Mo: >I j's think < (I was) just picking up (.) things along the way

Dr: Mm hm

Mo: We (.) just basic'ly decided to eliminate

Dr: Mm hm

Mo: the possibility

Dr: Mm hm (0.7)

Dr: So you really hadn't got- had great problems until he'd got to schoo:l (mm) °is'at right°

The interaction within this account is interpreted as representing the mother adopting a scientific process of deduction through collecting data and evidence “just picking things up along the way,” in order to refute the conjecture that she was overly concerned. “Problems” are identified, and tied to school, but not, as yet, identified as ADHD. In combination with analysis of the remainder of the interview, this local instance of talk-in-interaction is used to examine how routine and mundane it is for children to be positively diagnosed and medicated merely on presentation with the possibility of ADHD, even when parents are manifestly skeptical about the diagnosis (McHoul and Rapley 2005).

3 Foucauldian Discourse Analysis

Foucauldian discourse analysis (FDA) originates within poststructuralist theory, influenced by the philosophical work of Michel Foucault (1972). Within FDA, discourses are described as “sets of statements that constitute objects and an array of subject positions” (Parker 1994, p. 245) that are “a product of social factors, of powers and processes, rather than an individual's set of ideas” (Hollway 1983, p. 231). Language is deemed to be constitutive of social life, making available certain subject positions, which influence and regulate subjectivity and experience – the way we think or feel, our sense of self, and the practices in which we engage (Gavey 1989). FDA is, thus, concerned with identifying discourses, the subject positions they open up (or disallow), and the implications of such positioning for subjectivity and social practice, rather than the form or structure of interaction within talk or text. This includes analysis of expert discourse and institutional practice, talk generated through interviews, diaries or group discussions, and broader cultural representations.

In contrast to the DP focus on interpersonal communication, FDA centers on the examination of the relationship *between* discourse, subjectivity, practice, and the material conditions within which experience takes place (Willig 2008). This leads to attention being paid to wider social processes and power and how social order and the political realm is produced and reproduced through discourse. For example, the biomedical discourse, which positions health professionals (in particular doctors) as all-knowing and powerful, and health problems as pathologies to be eradicated through expert intervention, has been identified as one of the most powerful discourses in the field of health and illness (Foucault 1987). Legitimizing the subject positions “expert” and “patient,” it leads to a focus on somatic or psychological “symptoms,” which are deemed

to be located within the individual, and conceptualized in a realist manner as existing outside of language or cultural interpretation (Fee 2000). Thus, individuals who experience changes in mood, sleep patterns, or energy, and who report such changes to a medical practitioner, are positioned as “depressive,” and their future experiences interpreted through a medical lens, when they may have previously normalized or accepted such changes (LaFrance 2007). This positioning of emotional and behavioral changes as psychiatric illness, or madness, can be identified as serving to maintain the boundaries of normality, leading to self-policing on the part of the individual, in order to avoid diagnosis (Ussher 2011), or to return to “normality” after diagnosis is given.

In this vein, FDA has been used to examine expert accounts of diagnosis or treatment (Larsson et al. 2012), broader cultural representations (Bilić and Georgaca 2007), and lay experiences of psychological distress or diagnosis (LaFrance 2007). In each example, FDA is used to identify the multiple and sometimes contradictory subject positions adopted, the implications of these subject positions for subjectivity, and their association with broader social discourse.

Physical health and health behavior has also been subjected to FDA, including a deconstruction of the meaning of being an un/healthy fat woman (Tischner and Malson 2012), negotiating sexual changes after cancer (Ussher et al. 2013; Parton et al. 2017), and representations of menopause in medical textbooks (Niland and Lyons 2011).

As part of a FDA analysis, attention is often paid to the relationship between discourse and institutions, or institutional practice, described as “ways of organising, regulating and administering social life” (Willig 2008, p. 113). For example, the proliferation of psychiatric diagnosis through the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM) serves to maintain the authority of the “psy-professions” – psychiatry and psychology – the experts who are legally empowered to execute psychiatric judgment and administer “treatment.” The development of new diagnostic categories in every edition of DSM also serves to shore up the power and profits of BigPharma, the drug companies that sponsor the experts, who create the diagnostic categories, which new drugs are then developed to treat.

Within FDA, attention is also paid to the ways in which discourses change over time, the *genealogy* of discourse and discursive practice. For example, the development of the modern clinical diagnosis “anorexia nervosa” can be traced to historical accounts of “fasting girls” (Malson 1998), and the diagnostic category premenstrual dysphoric disorder (PMDD) traced to diagnoses of hysteria and neurasthenia, as well as to nineteenth-century pronouncements on the vagaries of menstruation (Ussher 2006). This genealogical analysis identifies continuities in both discourse and discursive practice – in both of the examples cited above, these practices center upon the pathologization and regulation of the female body, and the maintenance of the boundaries of acceptable femininity. FDA has been influential in feminist health research (Gavey 1989; Hollway 1989) because of its ability to be used in the analysis of the gendered construction of subjectivity, power relations, and social practice. However, feminist health researchers have also adopted DP in analyzing expert and lay accounts (Sheriff and Weatherall 2009; LaFrance et al. 2017), as discursive practice is also often gendered, and thus research arising from both DP and FDA traditions is described as “feminist discourse analysis” (Gavey 2011).

4 Synthesizing DA and FDA: A Combined Approach

Whilst many reviewers and discourse analysts distinguish between discursive psychology and FDA (e.g., Burr 2003; Potter 2004; Willig 2008), it has also been argued that the two strands should not be differentiated so sharply and that the analysis of discursive practices and resources should be combined (Rapley 2004; Sims-Schouten et al. 2007). For example, Margaret Wetherell (1998) has argued for a synthesis of the two approaches, “which reads one in terms of the other” (p. 388). Sims-Schouten and colleagues (2007) have combined discursive psychology and FDA in their description of a critical realist discourse analysis, and Rapley (2004) used a combination of discursive psychology and Foucauldian theory in analyzing constructions of disability. These approaches examine both discursive practices, the performative qualities of discourse, and the role of discourse in the constitution of subjectivity, self-hood, and power relations (Willig 2000).

At the same time, across both DP and FDA, differences can be identified between those who conduct fine grained analysis of selected sections of talk or text, using either DP or FDA (for example, Potter 2004; McHoul and Rapley 2005), and those who combine elements of thematic analysis with discourse analysis (see also ► Chap. 48, “Thematic Analysis”). The latter focuses on identifying discursive themes across accounts through thematic decomposition (Stenner 1993; Parton et al. 2016; Churrua et al. 2017), or within individual cases, described as thematic composition (Watts et al. 2009).

5 Defining Discourse Analytic Methods

This leads to the question: how do you do discourse analysis, and how does it differ across the different strands? There is no simple recipe, which can make discourse analysis seem daunting to the novice researcher. Parker (1992) provides a detailed 20 step guide for conducting FDA, which Willig (2008) has simplified into a six stage guide, as well as providing three steps for DP analysis. Potter and Wetherell (1987) provide details of 10 stages of discourse analysis, which later came to be known as DP, but also argue that it is reliant upon “intuition,” craft skills and tacit knowledge and that there is “no analytic method” (p. 169). Similarly, Hollway (1989) emphasizes her own intuitive feelings about the identification of discourse, and Billig (1997) argues that discourse analysis cannot be simply learnt as a procedure, separate from its wider theoretical critique of psychology, and that methodological guidelines should not be followed too rigidly. It has also been argued that the process of analysis and writing are not separate, as analysis will be refined and clarified throughout the writing process (Potter and Wetherell 1987).

With these caveats in mind, in Table 1 below we provide a general summary of steps in the process of conducting discourse analysis, drawing on the guidelines provided by Willig (2008) and Potter and Wetherell (1987), with distinctions between DP and FDA indicated in the analysis section. We then provide a

Table 1 Components of discourse analysis

Reading: Read through transcripts, and listen to interview recordings, to gain an overview of the data, and what the text is doing. For textual analysis, read through texts or representations.

Coding: Select the material for analysis, using the research questions as the basis for selection. Develop a coding frame, based on reading and re-reading of the data. Highlight and select relevant text and file it under the coding frame. Computer software, such as NVivo, can be used to manage the organization of coded data (see also ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”).

Analysis: Read through the coded data, paying attention to the functional aspects of discourse: how does the text construct subjects and objects? What is the discursive context within which the account is produced? Are there contradictions or variability in the accounts? Can particular discursive themes, or interpretative repertoires, be identified?

Discursive Psychology: *Focus of analysis:* How are particular versions of reality manufactured, negotiated and deployed in conversation?

Steps: What terminology is used; what are the stylistic and grammatical features, the preferred metaphors and figures of speech? What is the action orientation of the account – what people do with language? How is meaning negotiated in local interaction?

Foucauldian Discourse Analysis: *Focus of analysis:* Examine the social, psychological, and physical effects of discourse; the availability of discourses within a culture and the implications for those within.

Steps: Discourse and discursive constructions: Locate the various discursive constructions of the object, and identify their association with wider cultural discourses. If conducting a genealogy, examine the historical development of such discourses and discursive practices. *Function:* What is the function of such constructions? What is gained by constructing the object in this way?

Positioning: what subject positions are offered by the text? *Practice:* how does discourse open up or close down opportunities for action? What are the implications in terms of power relations?

Subjectivity: what are the consequences of taking up, or resisting, subject positions made available? What can be thought, felt, or experienced from within various discourses?

Writing: Contextualize your research in the context of other DA studies using a similar method. Provide details of theory and method adopted: how you did the analysis.

Depending on the research question, focus the analysis on the identification of discourses (or interpretative repertoires) in talk or representation; on the discursive construction of objects (such as menopause) and/or subject positions (such as “aging woman”); or on discursive strategies and their consequences. Illustrate each with examples from the data. Analysis and discussion sections are often combined, with a separate shorter conclusion section drawing out the wider theoretical implications and suggestions for future research.

description of a Foucauldian discourse analysis of women’s negotiation of negative premenstrual change, as an illustration of how this analysis can function in practice.

6 Analyzing Premenstrual Distress: A Feminist Discourse Analysis

6.1 Study Aim and Method

The aim of this study is to examine women’s construction and negotiation of negative premenstrual change. The research involved 60 heterosexual and lesbian women who were taking part in a mixed method study examining the construction

and experience of premenstrual change in self-diagnosed Premenstrual Syndrome (PMS) sufferers (Ussher and Perz 2013). We conducted one-to-one semi-structured interviews, which lasted between 45 and 90 mins. We kept the interview questions open and general to avoid being leading and conducted the interview as a discussion between interviewer and participant. The interviewer began by asking women to describe a typical experience of PMS and how this varied across relational contexts, and then explored strategies of coping. In the analysis, we adopted a feminist FDA approach, which examines the role of discourse in the constitution of subjectivity and social practice, while also acknowledging the material conditions which influence such experiences, and the role of discourse in wider social processes of legitimation and power (Gavey 1989, 2011).

6.1.1 Reading and Coding

All of the interviews were transcribed verbatim. A subset of the interviews were then read and reread by both authors and a research assistant to identify first order codes, such as “embodied changes,” “emotional distress,” “relational issues,” “PMS at work,” “coping,” and “triggers for premenstrual distress.” The entire data set was then coded using NVivo, a computer package that facilitates organization of coded qualitative data.

6.1.2 Analysis

All of the coded data was then read through independently by both authors, making detailed notes of patterns, commonalities, variability across the data, and uniqueness within cases. This was a reflexive process that allowed us to interpret participant accounts from our different perspectives: as a woman who experienced premenstrual change (Ussher) and one who did not (Perz). Through a process of discussion, we then identified the discursive constructions of PMS and premenstrual change in the context of broader cultural discourse. These constructions included PMS as illness, as sign of weakness, as natural, and as a relational experience. The function these discourses served for women and for their partners was identified, and attention paid to the subject positions made available through various discursive constructions of premenstrual change. The implications of discursive constructions for practice, in particular for styles of coping, and power relations in both a relational and broader social context were also examined. Finally, the consequences of taking up or resisting subject positions, in terms of women’s subjectivity, were attended to: women’s accounts of thoughts or feelings, and of self-hood, from various discursive positions. The genealogy of discursive constructions of PMS is examined elsewhere (Ussher 2006).

6.2 Women’s Descriptions of Premenstrual Change

All of the women interviewed described premenstrual change as “PMS,” characterized by heightened premenstrual irritability, intolerance of others, and oversensitivity, using terms such as “irritable,” “cranky,” “short-tempered,” “snappy,”

Table 2 A feminist Foucauldian discourse analysis of PMS

Discursive construction	PMS as pathology	PMS as an understandable reaction
Discourses	Biomedical	Feminist psycho-social
Function	PMS as a thing that causes distress Locates PMS within the body Exonerates women from unacceptable anger	Locates PMS within relationships or life stress Legitimizes expression of premenstrual needs and emotions Tolerance and normalization of premenstrual change
Positioning	Woman as out of control Victim of hormonal imbalances Woman as monster; abject	Woman as agentic and rebellious Woman as sensitive or vulnerable premenstrually
Practice	Pharmaceutical interventions Avoidance to protect others Premenstrual self-control and self-silencing	Legitimizing time-out and avoidance for self-care Attention to situational issues associated with distress Rejection of acquiescent femininity
Subjectivity	Self-blame and guilt Shame	Acceptance of premenstrual emotions Catharsis

“confrontational,” having a “short fuse,” “bitey,” “impatient,” “grumpy,” “stroppy,” “frustrated,” “stressed” “annoyed,” or “teary.” However, how women discursively positioned these changes, and the implications for subjectivity, self-positioning and practice, varied. Two discursive constructions of PMS identified in women’s accounts are presented below: PMS as pathology, drawing on biomedical discourse, and leading to a victim or monster subject position; and PMS as an understandable reaction, drawing on a feminist life-stress discourse, which facilitated tolerance and self-care, as summarized in Table 2.

6.3 Premenstrual Change as Pathology: Woman as Victim or Monster

When you’re being taxed physically by the PMS, because it does something, I don’t know what it does, whether it. . . I know it depletes certain vitamins and you’ve got low magnesium and this and this and this and that, and your hormones can be off, and not where they should be. And I think just that being taxed with those things helps you, or makes you not be able to handle other things, where if you’re not taxed with all that, you can handle other difficulties that you’d normally be able to handle.

6.3.1 Discourse and Discursive Constructions

The construction of premenstrual change as pathology, drawing on a biomedical discourse, is illustrated in the above account. PMS is described as a thing (“the PMS”) that results in the woman’s inability to handle daily stresses that she is “taxed” with, and which she would “normally” be able to handle. PMS is blamed

for depleting “certain vitamins” and for causing hormones to be “off.” This “thingifying” of PMS has been previously identified in published expert accounts of premenstrual change (Ussher 2003), demonstrating that women are drawing on wider cultural discourses in adopting this construction of premenstrual change. This serves to position PMS as the *cause* of women’s premenstrual distress, rather than a label which is given to an array of premenstrual changes that women may report.

6.3.2 Function and Positioning

We asked what is the function of such constructions? and what is gained, or lost, by constructing premenstrual change in such a manner? One of the implications of the adoption of a biomedical discourse is the self-positioning of the premenstrual woman as “out of control” and a victim of her hormonal “imbalances,” as is evident in the account below:

The imbalances were happening in the body and all that sort of stuff that I had absolutely no control over. I mean, sure, I had other issues I had to contend with, but I was dealing with that so, to me, this was something that was so out of my control that I felt like I was being blamed for actually knowing how to deal with it, and it’s like, ‘Well, I don’t.’

Through reading the coded data, we identified a process of splitting, wherein women discursively separate their normal sane selves from the abhorrent nature of premenstrual emotion, thus exonerating themselves for what they construe to be mad or bad behavior. Extreme descriptions of the premenstrual self were used to illustrate the dramatic nature of this change, including “crazy,” “mad,” a “nut case,” “absolute psycho,” “Schizo,” “out of my mind,” or “a complete loony.” Positioning the premenstrual self as mad serves to reinforce the notion of premenstrual changes as outside of the woman’s agency, and as someone whose behavior is a sign of pathology:

You’re like a person that’s probably, you know a crazy drunk that’s had a lot of alcohol or on pot, really high on drugs and they just snap and you can’t control their anger. I would um react like that, without having had anything.

However, the expression of premenstrual irritation or anger was invariably followed by reports of guilt and self-criticism, suggesting that self-positioning as afflicted by hormones premenstrually is not effectively serving to exonerate women from “bad” behavior, as previously suggested. Thus, one woman told us, “(Y)ou feel horrible about it the next week. . . it makes you feel sick,” and another said she feels “really upset” and “angry” with herself. This is associated with shame, and with a sense of the need to apologize, which involves woman taking up a position of abjection:

There’s fair bit of violence coming through in all of this isn’t there. Throwing things, um, venting a frustration and trying to learn to control these things so that people don’t look at

you funny and you don't make a fool of yourself which you later regret. When you come back to normality, you think, um, I've got to go around and apologise to all these people I've just bitten their heads off over absolutely nothing. No, it's, in the back of your head you know what's normal.

6.3.3 Practice

We asked what are the implications of this positioning in terms of women's coping strategies in the face of negative premenstrual change? What opportunities for action are made available by the subject positions women adopt?

Biomedical constructions of PMS leave women with one obvious opportunity for action: pharmaceutical interventions. In this vein, we identified that women who adopted a biomedical discourse talked of taking self-prescribed herbs (such as St John's Wort, Vitex, or evening primrose oil), and vitamins, or minerals (in particular B complex and magnesium), as part of their premenstrual self-care. A small minority of women had also been prescribed the contraceptive pill, with one participant prescribed antidepressants, to reduce premenstrual distress. The majority reported satisfaction with such remedies, reinforcing the positioning of PMS as a bio-medical phenomenon which can be treated: "I know that I wouldn't cope too well if I wasn't on St Johns Wort which has helped me 100%"; "I think if I remember to take them, like, as I should, I mostly get away without almost without any symptoms."

6.3.4 Implications for Power Relations

These strategies served to position women as dependent upon medical advice and intervention, as "patients" whose bodies are the focus of intervention. However, all of these dietary supplement or pharmaceutical coping strategies were also accompanied by psychological or behavioral strategies, demonstrating that the adoption of a bio-medical discourse does not inevitably preclude women's agency. This is analogous to the "tight-rope talk" identified by Sue McKenzie-Mohr and Michelle Lafrance (2011), wherein women construct themselves as both "agents and patients: both active and acted upon" (p. 64), enabling credit for agency in coping and deflection of blame for "having" PMS.

The coping strategy most commonly reported by participants was avoidance of people or situations that had the potential to provoke anger and irritation. For example, one woman told us, "the kids . . . I try not to get into conflict, into confrontation with them." Anticipation or avoidance of stressful situations is not always possible, however, and many participants gave accounts of experiencing unexpected situations that elicited premenstrual anger or irritation. As a result, they described coping with occurrences of negative premenstrual emotion through exertion of self-control, leaving a situation when they had become angry, in order to avoid escalation of conflict.

I usually feel stressed in the lead up. If it gets to the point where I actually need to say that, I know the pressure cooker, little thing on the top bouncing up and down, you know, um at that

point and it's almost like a last resort for me. If I know I'm going to explode, I try to train myself to step back and chill.

In some accounts, self-control was described as necessary for the protection of others, reinforcing the positioning of the woman as monstrous and out of control. For example, one woman described "hibernating," because of a fear of not being able to "rein yourself in," and wanting to avoid "hurting people with words," because "it's not their fault."

6.3.5 Subjectivity

The consequence of constructing premenstrual change as pathology, and adopting a biomedical discourse, was that women reported shame and dislike of the self during the premenstrual phase of the cycle. The body was a focus of negative emotion, being blamed for women's distress, and disconnected from the self: "I feel quite odd and almost out of body"; "you feel like you're a blimp um even though you feel ugly and this is this is all PMS."

6.4 PMS as an Understandable Reaction: Facilitating Agency and Self-Care

P. I get very snappy and short with people I know... you know... um... yeah, things that normally don't bother me, bother me. It tends to be about housework, and my role as a woman, and why do I have to do all of this and... yeah. Things that I kind of repress... come out to the surface.

I. Okay.

P. That's what I've found.

I. Okay. So they're not things that aren't there the rest of the time and suddenly they appear, they're things that you think are...?

P. They're underlying. They're underlying issues and I just kind of tick along nicely and think, "Well, you know, it's okay, I can deal with it," and then, PMS comes and I can't deal with it. Yeah.

6.4.1 Discourse and Discursive Constructions

In contrast, in the account above, premenstrual emotion is described as a reflection of a woman's anger or frustration with "underlying issues" associated with domestic concerns and her "role as a woman." This reflects the adoption of a feminist psycho-social discourse, wherein gendered inequalities and over-responsibility are positioned as a cause of women's distress, and anger or frustration is deemed to be a legitimate reaction. A similar construction of PMS was adopted in accounts of intolerance or anger towards male partners premenstrually. For example, one woman described her husband as "a bit of a hoarder and a collector, and 3 weeks of the month that does not bother me." However, when premenstrual, she said, "it bothers me a lot and I want to throw everything out, to put everything into plastic bags and dump it on his desk [laughs]."

6.4.2 Function

One of the primary functions of adoption of a feminist psycho-social discourse was to position premenstrual emotions as understandable and reasonable, resisting the discursive positioning of the premenstrual woman as mad, bad, or dangerous (Chrisler and Caplan 2002). Thus, one woman described awareness of premenstrual sensitivity as “a weight off my mind. ‘Cause at first I used to think I was going a little crazy. . . it’s helped me deal with, ‘those are PMS feelings’.” Similarly, another woman tells herself, “Oh, OK, I know now, you’re not actually the wicked witch.” This construction of PMS was also associated with tolerance of negative premenstrual change, which could then be normalized, or embraced as an “opportunity” to “be emotional”:

I think I embrace it as an opportunity to, um, just rest and, um, be more in tune with myself, and be emotional. I think I was probably fighting being emotional in the past, and that’s what caused so much discomfort and stress.

Recognition and acceptance of negative premenstrual change can also function to give women permission to engage in coping strategies to avoid or reduce premenstrual distress – without a sense of guilt. Thus, one woman told us: “I’ll actually give myself permission to actually go and lie down for half an hour. Even half an hour will make substantial amount of difference.”

6.4.3 Positioning and Subjectivity

In these accounts, women not only avoid taking up a subject position of victim or patient, wherein their bodies (or minds) warrant medical treatment, they also subvert the self-surveillance which they adopt for the remainder of the month (see Ussher and Perz 2010). Implicit in these accounts is the transgression of self-silencing, which is broken when PMS “comes” along.

6.4.4 Implications for Power Relations

Premenstrual emotional expression is associated with a sense of catharsis. In this way, “PMS” signifies rebellion and resistance, rather than weakness and pathology, and breaks in self-silencing are a sign of women’s agency.

This case example illustrates the ways in which discourse analysis can be used to understand the construction and experience of a specific health issue, as well as the role of language in the course of distress, and in facilitating coping.

7 Conclusion and Future Directions

Discourse analysis has a relatively short history in the Health Social Sciences, but has had a significant impact upon the conceptualization of the sick or healthy subject and on the conduct of qualitative research. Discourse analysis offers the opportunity to explore the construction of health and illness within a range of cultural representations and expert accounts, the meaning and experience of health and illness for lay-people, and the implications of discursive constructions of health and illness for

subjectivity. There is no one correct method of discourse analysis, as multiple methods have been identified (Wetherell 2001), and practitioners interpret and present analyses in a range of different ways. This flexibility is its strength in the Health Social Sciences, given the uniqueness of health problems. This chapter has summarized two identifiable strands of DA, discursive psychology and Foucauldian discourse analysis, and presented one interpretation of feminist FDA as an example. However, the specific form of DA adopted will always be determined by the research questions that drive a project, with the mode of analysis and presentation influenced by the theoretical orientation, skills, and creativity of the researcher.

Future directions include the integration of a range of nontextual methodologies alongside or instead of analysis of interview or written text, including photography (Triandafilidis et al. 2017b), body-mapping, and other arts-based methods (Boydell et al. 2016). The move towards an intersectional analysis (Hankivsky and Cormier 2009) in feminist research has resulted in discourse analysis, with its attention to complexity of subjectivity and experience, the negotiation of multiple and potentially contradictory subject positions, and the importance of power relationships, becoming the qualitative research method of choice. As critical Health Social Scientists also embrace intersectionality, discourse analysis may also become the preferred method of qualitative analysis in the Health Social Sciences.

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Schema Analysis of Qualitative Data: A Team-Based Approach

51

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Contents

1	Introduction	898
2	What Is Schema Analysis?	900
3	The Schema Analysis Process	901
3.1	Stage 1: Constructing Individual Schemas	901
3.2	Stage 2: Group Work and the Development of Group or “Meta-schemas”	903
3.3	Stage 3: Interpretation of Meta-schemas	904
4	An Exemplar: The Role of Multidisciplinary Teams in Breast Cancer Risk Communication	905
4.1	Stage 1: Individual Schemas	905
4.2	Stage 2: The Group or Meta-schema	908
4.3	Stage 3: Interpretation of Meta-schema	911
5	Validity, Rigor, and Trustworthiness of Data	912
6	Lessons Learned: Enriching Qualitative Analytic Practices	912
7	Conclusion and Future Directions	913
	References	914

Abstract

Schema analysis is a novel, qualitative data analysis technique that uses a summative approach to make sense of complex, nuanced, textual data. It aims to ensure that key features of a text, or “essential elements,” are revealed *before* any interpretation of

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897

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those key elements takes place, based on the assertion that data should be handled in a principled, informed, and strategic manner to achieve phenomenal clarity. Teamwork is a central element of schema analysis, enabling researchers to effectively co-create meaning across disciplinary boundaries through consensus-driven strategies. The research team's shared accountability for interpretive decisions is clearly linked to a study's original questions and the research team's desire to be rigorous in their collaborative stance and equally vocal. Schema analysis can be used in the context of a wide range of qualitative studies or can sit alongside outputs from other mixed-methods studies to add substance to their findings. The technique has been successfully developed and refined by the lead author, to suit a wide variety of healthcare scenarios, evidenced by published research projects from UK and Australian contexts. In this chapter, the method is presented in detail, step by step. An example of the use of schema analysis in practice is offered up from a recent Australian study that examined multidisciplinary team-working practices in oncology. Study data from an interview with an oncology psychologist working as part of an oncological multidisciplinary team is considered, to reveal how healthcare professionals present information about risk to women with breast cancer. The chapter considers methodological implications for achieving validity and rigor, upholding trustworthiness in data, and creating data that are transferable to different settings. To conclude, the chapter reflects on future opportunities for the method's use in qualitative research.

Keywords

Schema analysis · Team-working · Qualitative data · Consensus-driven approach

1 Introduction

Schema analysis is a novel, qualitative data analysis technique that uses a summative approach to make sense of complex, nuanced, qualitative data. It concentrates on qualitative data in textual form only and aims to ensure that the key features of a text, or “essential elements,” are revealed *before* any interpretation of those key elements takes place. Schema analysis is dependent on accurate descriptions of data content that can be used in the context of wider qualitative studies or that can sit alongside outputs from mixed-methods studies.

Schema analysis derives from the notion that data should be handled in a principled, informed, and strategic manner (Rapport 2010). Accountability, regarding the decisions that are made, lies with all the researchers involved. As this is a group-working method, people's roles are equivocal. The group comes together out of a shared need to understand a text or a number of texts, in their fullest expression, while wishing to derive an essential understanding of each piece of text, to achieve “phenomenal clarity.” Thus, being accountable for decisions made is clearly linked, not only to the original study questions but to the researchers' desire to be rigorous and equally vocal, gained by abiding to methodological principles of how to create schema.

Schema analysis was developed by Frances Rapport (first author) and helped to refine her summative analysis method (Rapport 2010). It was the result of the need to

handle and manage difficult and complex datasets that had been collected from disenfranchised and often dispersed population groups (Rapport 2010). It was developed, first, as a group activity to manage qualitative data from extended focus groups with women with breast cancer who were exploring the value of decision aids to support complex treatment choices (Rapport et al. 2006; Iredale et al. 2008) and was adapted, over the next 10 years, to fit various summative analytic styles. The development of schema analysis also influenced co-joint working practices, such as those undertaken by Rapport and Sparkes (2009) and Rapport and Hartill (2010, 2016) to examine survivor's life and health trajectories following the trauma of overcoming an extraordinary event such as the Holocaust. Finally, it took account of others' writings on, for example, thematic analysis (Ryan and Bernard 2000), the use of oral and written testimony in research (see, e.g., "talk and text" (Silverman 2000)), and the research participant's role in research (see, e.g., Fleming and Ward 2017). More latterly, schema analysis has been adapted as a result of Rapport's involvement in Nominal Group Work (NGW) activity, through multiple stakeholder group consultations (Rapport et al. 2010, 2015).

Teamwork is a central element of schema analysis, enabling researchers to effectively co-create meaning across disciplinary boundaries (what this authorship group calls "meaning-making in the round"). This leads to narratively rich, impactful, and highly original outputs. Furthermore, by working collaboratively and on a basis of equality, the final research product (irrespective of form) will enhance the meaning-making activity.

In order to achieve an inclusive research process, in a multidisciplinary context, through clear research collaboration, it is important for the method to be adaptable to different group dynamics and inclusive of all involved. Schema analysis achieves this through its versatility, accommodating those working in both public and professional domains. The method is clearly defined for all involved and purposefully inclusive of people who only have a general interest in qualitative research methods or very little qualitative analytic experience. Consequently, irrespective of one's knowledge base or expertise, the process is clearly defined for all to contribute.

A clinician or consumer can fully immerse themselves in team-working, while other researchers can learn more about their own topic of interest from laypeople or healthcare professionals, using what is learned to inform their own research. Thus, the method is adaptable and impactful and should be widely available to academics, researchers, and students who may wish to apply it within their own work or educators and policy-makers to explore educational opportunities or societal effects.

Schema analysis has developed around the principles of equality, availability, and malleability. The method has to be appropriate across a variety of disciplinary fields, such as the sciences, social sciences, and humanities. In order to ensure that this is the case, it foregrounds the need for clearly labeled decision trails, transferable and practical outcomes, and transparent, interdisciplinary working methods and backgrounds hierarchical working methods.

In this chapter, we present the method in detail, step by step. We reveal the implications for research validity, rigor, and the trustworthiness of data, and we highlight how the method can be used. We present an example of the method in use from a recent study examining multidisciplinary team-working practices and

presentations of risk to women with breast cancer in an Australian healthcare context. To conclude, we consider opportunities for the use of this method in qualitative research.

2 What Is Schema Analysis?

Schema analysis is a way of summarizing, and then offering a clear and succinct presentation, of the essential elements within an original text. It uses group-working activities with groups of researchers revealing essential textual elements in data before interpreting what data means. It avoids preemptive, superimposed meaning-making, refraining from either breaking text down into small chunks (as with thematic analysis) or presenting text through authorial presence (as with realist tales). By so doing, it captures essential elements of a text richly and fluidly, without losing any of the original text's nuance or ambiguity. It uses group-working activities to derive succinct, collaboratively created textual overviews that, once created, can then be examined for their underlying meaning. These are known as group schemas (or "meta-schemas"), and once created, they can be fully interpreted, to inform study reports or publications.

Analysis is applicable to any raw textual material but, most commonly, works best with interview transcripts, biographies, autobiographies, or focus group reports. Group schemas are co-created by members of a research team who work together towards well-crafted and concise summaries, paying particular attention to the inclusion of person-focused, topic-sensitive, verbatim quotations. Schema analysis is underpinned by ongoing teamwork meetings (also known as workshops), so sense-making is built over time, iteratively and through ongoing debate. During workshops, team members must agree on which aspects of the raw material to retain and which to lose. Views are presented, discussed, and negotiated. Ideas become refined, as raw materials are honed down into their core components, and are narratively presentative. At the same time, schema analysis offers a way of handling large quantities of qualitative data succinctly, ensuring they can be reduced to easy-to-follow half-page presentations that encapsulate a holistic understanding of each full piece of text while revealing the key features it holds.

Schema analysis is wholly dependent on the ethos of group-working. Researchers move quickly from an individual consideration of data to a shared understanding. The wider team (optimally no more than six people) come together to read one another's work. This is followed by an assessment of how the group compliments one another or how views are contrasted. Qualitative researchers are encouraged to not only discuss the raw material with one another but also their own personal views – the impact of the "self" on data, in a desire to withhold personal preconceptions or assumptions. Consequently, schema analysis depends on honesty and openness from the whole team, often with a senior academic overseeing this aspect of group work. At the same time, individuals are encouraged to keep a study diary noting personal presuppositions as they work, changes to these over time, and their views of others' opinions. This aids individual awareness, helps the senior academic to manage the

group-working activity most effectively, and encourages team members to move smoothly from an individual narrative to a meta-schema.

This approach significantly differs from many other qualitative methods, such as the creation of a standard or “realist” tale. The realist tale, as Andrew Sparkes (2002) reminds us, when well-constructed, can provide a useful, compelling, and detailed depiction of one’s own or another’s social world (see also ► [Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility”](#)). Realist tales are powerful ways of presenting qualitative data but are, nevertheless, predicated on the presentation of a single viewpoint. They are wholly dependent on experiential authority and the interpretive omnipotence of a single researcher. Unlike the realist tale, neither summative analysis (Rapport 2010) nor schema analysis (its most recent derivation) accepts the authorial presence of interpreter omnipotence, nor do they abide by the backgrounding of others’ intentions, to allow for an unchallenged authority on data or its interpretative aspirations (Van Manen 1998; Sparkes 2002). On the contrary, schema analysis moves away from the notion of being overly deterministic, to provide opportunities for a group’s shared creativity.

Schema analysis also differs from thematic analysis, which concentrates on codifying data into themes and their concomitant categories. Thematic analysis works by breaking data down into small chunks, or “meaning units,” and by applying techniques such as line-by-line coding, and code-nesting, which classifies meaning units under thematic headings. This tends to place themes in clear silos, each separated and demarcated (see also ► [Chap. 48, “Thematic Analysis”](#)). Thematic analysis can, as a result, run the danger of decontextualizing data, often failing to resituate data in their wider context, and missing out on “whole-body” presentations of meaning.

Schema analysis avoids the unnecessary dissolution and discombobulation of text by emphasizing the need to continue to review narratives holistically. It is worth noting, however, that schema analysis can be an excellent way of complementing a thematic analysis or a realist tale, with outputs open to comparison across methods.

3 The Schema Analysis Process

There are three stages to schema analysis: Stage 1, the development of individual summative schemas; Stage 2, the development of meta-schemas from the individual schemas; and Stage 3, the development of interpretive accounts from the meta-schemas. Figure 1 illustrates the three stages involved.

3.1 Stage 1: Constructing Individual Schemas

In Stage 1, individual schemas are developed by individual analysts. These are people who have been brought together by a senior academic, or team leader, identified according to their interest in the topic, what they hold in common, or the different qualities they can bring to the group. Groups of co-researchers may be

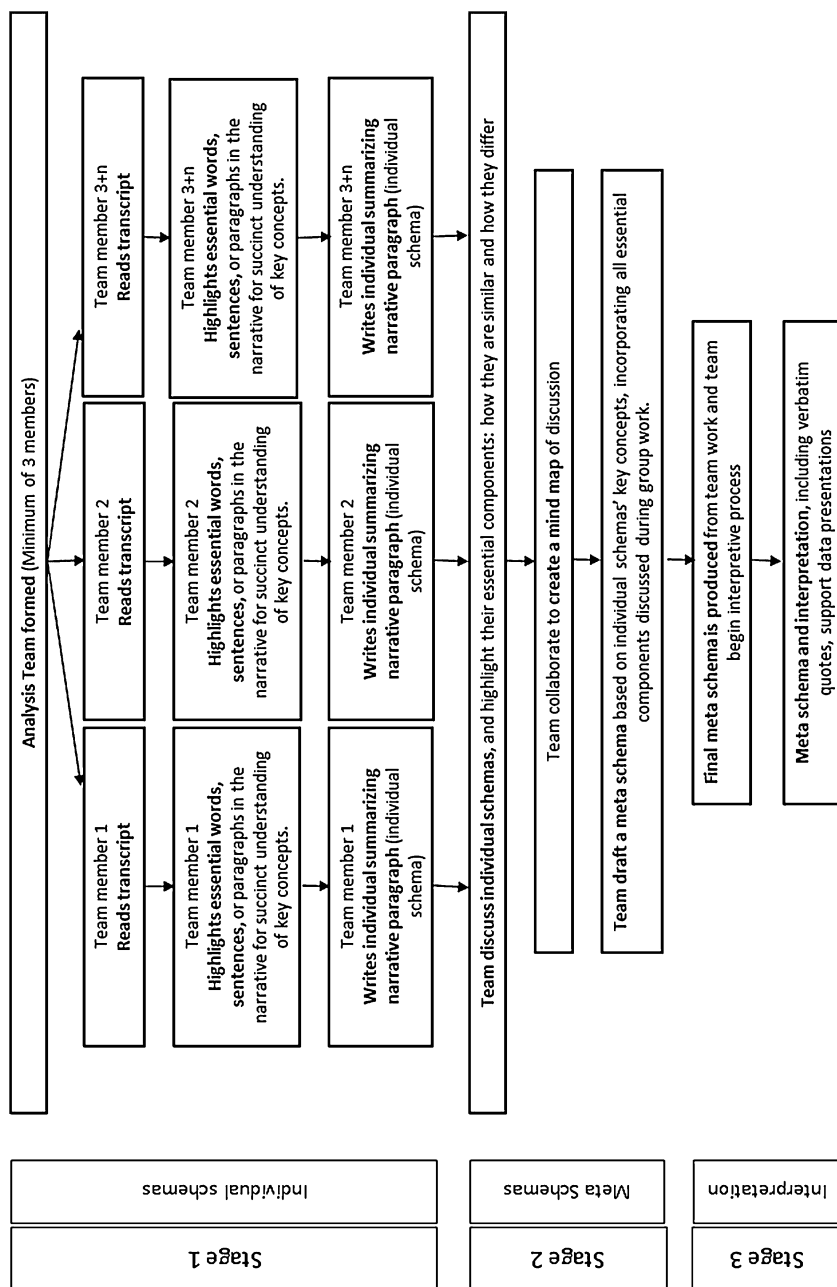


Fig. 1 Simplified presentation of schema analysis, an in-depth teamwork analysis process (Adapted from Rapport et al. [under review](#))

selected for a variety of reasons, such as (a) their homogeneity (familiarity with the topic, research question, or people involved), (b) their impartiality (coming from very different backgrounds, with different expertise and interests), or (c) their lack of knowledge of the topic. The choice of co-researchers, as with other group-working methods, is dependent on the individual study and the needs of the primary researcher or senior academic overseeing the work.

Each individual reviews the research data separately and, following their review, identifies the essential elements belying each piece of text. The essential elements (also known as a text's key features or critical moments) are those aspects that provide a point of entry into an understanding of the whole text. Rather than taking account of the individual analyst's personal view of the data, however, individual schemas should be written as an ongoing, free-flowing narrative that tells the story of the text, by weaving the key features together fluidly, and which presents the research participant's perspective in a vastly reduced form. The individual analyst's schema should concentrate on the participant's use of words and phrasing (their "ordinary language"), while schemas show interweave their own writing with quotations, to add richness and individuality to each piece.

Essential elements of a text do not purport to a single, critical "truth" but together offer a composite picture that contains multiple truths, all of which go equally toward an understanding of the whole. They must be considered in their own right, as critical component parts, which once revealed, can be fully accounted for through the group-working activity to follow. Thus, it could be said that the essential elements are those without which the topic (the phenomenon) would lack its full coherence and cannot be comprehensively defined or revealed in all of its complexity and uniqueness.

From individual schemas, succinct group schemas (or meta-schemas) are crafted (see Stage 2 below), and individuals create one schema for every piece of text examined, each approximately half an A4 page in length, ready for sharing with others (Stage 2).

3.2 Stage 2: Group Work and the Development of Group or "Meta-schemas"

Team-working, in Stage 2, allows multiple perspectives to come to the fore (Mauthner and Doucet 2008). Teamwork takes place over an extended period of time. The team meets through multiple workshops to take part in consensus-building discussions. From individual schemas, meta-schemas must include the original text's essential elements with full agreement from all present. Stage 2 begins with discussions of each individual's schema, while each individual's view is compared and contrasted with the views of every other person in the group. The group must agree on which aspects of a text to hold dear and which to let go of. They must discuss which are essential, and which are incidental, which are outliers and which are critical experience, as well as which quotes support or undermine the essential elements in their holistic presentation. Agreeing on this takes time and is a consequence the desire to achieve consensus opinion must be paramount. Team members

learn to recognize, and take advantage of, the scope and value of all present and to enjoy the mutually beneficial, multidisciplinary, and collaborative process while discerning the impact of group understanding – more valuable than any one individual's perspective alone.

Data analysis in qualitative studies can often be a lonely and isolating experience, demanding long hours of solitary working. Individual researchers may occasionally seek help in making sense of the “bigger picture” (the broader understanding of their data), but this is rare. Similarly, only occasionally will a data analyst consult on the “minutiae” of data (a text's nuances, ambiguity, or unexpected revelations) or turn to a colleague or supervisor for assistance. More often than not, peer review is piecemeal, and while help can be forthcoming, others' input is temporary, leading to gains that are short-lived. The infrequent involvement of others can lead to an introspective activity that adds little to a researcher's sense of shared responsibility for data management and handling.

This is not the case in schema analysis. In creating and discussing individual and group schemas, through multiple workshops that take place over time, under the clear steerage of a senior academic with some expertise and yet no dominant worldview, everyone involved is fully and equally invested in the outcome. Researchers must, as a consequence, completely commit to the process, from the beginning to the end, and take equal responsibility for the end product, while sharing in the rewards.

3.3 Stage 3: Interpretation of Meta-schemas

The number of group schemas produced depends on the number of pieces of text being analyzed at any given time. The primary researcher or senior academic's role, on account of their knowledge of schema analysis, can, if necessary, be to manage the team, as long as members adhere closely to these three stages through self-direction and self-determination. This is wholly dependent on the makeup and needs of the team. Furthermore, team members can work on a sub-sample or the complete dataset, depending on the needs of the study.

Meta-schemas stand as a record of all the work that has gone before, and from their creation, interpretation of the phenomenon can be finally derived. Interpretation is avoided until Stage 3, where a final analysis of all meta-schemas through the triangulation of data takes place. From the group schemas, a comprehensive interpretable presentation of the whole dataset being studied is written in the form of a final report or publication that contains all group schemas and their interpretations. During Stage 3, time must be spent discussing meta-schemas in terms of the final study product, aiming to highlight the team's shared understandings and shared meanings derived across datasets. The interpretative stage, Stage 3, illustrates what the data has to offer, and indicates how study outputs may hold value for wider audiences, with potentially far-reaching consequences. At this stage, aspects of context can be brought to bear, with descriptions, in whatever format, including key quotations and revelations of setting and environment.

4 An Exemplar: The Role of Multidisciplinary Teams in Breast Cancer Risk Communication

In this section, we present an exemplar of the method in use. The study in question, approved by the Macquarie University's Human Research Ethics Committee (Reference Number 5201600446), was undertaken at the Australian Institute of Health Innovation (AIHI), Macquarie University, Sydney, to examine the role of multidisciplinary teams in breast cancer risk communication. It took place between 2016 and 2017, and in this exemplar we examine the views of one study participant, an oncology psychologist (who will be known under the pseudonym "Chloe"), who took part in a semi-structured, face-to-face interview with one of the study researchers (PS). The full team included four staff members from AIHI, a social scientist, an ethnographer, a biomedical scientist, and a clinically trained mixed-methods researcher (see Fig. 2 for detail).

The transcript of the interview described the role of the psychologist in a wider multidisciplinary team-working context, her responsibility to the breast cancer program, and how she understood and presented patients with the concept of "risk" as well as how she communicated with other colleagues. Within the transcript, the oncology psychologist also discussed her role in the multidisciplinary team and members' relationships with one another and with patients.

4.1 Stage 1: Individual Schemas

The team of researchers, with varied degree of qualitative research experience (see Fig. 2), developed the meta-schema from individual schemas and the interview transcript. The primary researcher accountable for the study (FR) oversaw the process, creating her own succinct overview of the data source (see Example 1). Concentrating on the perspective of the research participant, the individual schema





 <p>Frances Rapport (FR) Team lead/senior researcher</p> <ul style="list-style-type: none"> - Social scientist - Qualitative methodologist 	 <p>Patti Shih (PS) Data collection lead</p> <ul style="list-style-type: none"> - Sociologist - Ethnographer
 <p>Anne Hogden (AH) Schema analysis team member</p> <ul style="list-style-type: none"> - Clinically trained researcher - Mixed-methods researcher 	 <p>Mia Bierbaum (MB) Schema analysis team member</p> <ul style="list-style-type: none"> - Biomedical Science education - Mixed-methods researcher

Fig. 2 Roles and disciplinary backgrounds of the research team from Macquarie University responsible for the case study

offered a brief vignette of the text's content. It took the form of a coherent, free-flowing narrative of approximately a paragraph in length (half a page), and the approach was then taken up by each of the other researchers in the team who created their own individual schemas (see Example 2 for an example of one of the group member's schemas). Once these were created, they were circulated among the group, and an initial workshop was convened to discuss similarities and differences in individual's schemas' content and style and to compare and contrast the views of the group on the written exercise. Individual schemas were collated and distributed before the first workshop took place to give team members a chance to read each other's work and consider their content. The initial workshop led to extensive discussion of essential elements that differed in individual presentations.

Example 1 of an Individual Schema

The psychologist's primary role is to offer emotional support to patients and help them decipher what doctors have recommended, while clarifying underlying meanings expressed. Patients are appealing to the psychologist for: "insider knowledge" or an "informal opinion," hoping to gain clues about the minutiae of conversations with oncology specialists, while looking for translations of nonverbal inference. For the psychologist, discussing risk with patients is not about deciphering quantification. Rather, it is about assessing what patients are scared about, what they need to be reassured about, and what their tolerance level is for more information. The psychologist must assess how to bridge the gap between clinical team members' presentations, their actions and reactions to patients, and patients' expectations and understandings. The psychologist is the arbiter of the peace – there to direct patients along a steadier route than might otherwise have been the case. They are well aware that the patient is afraid of dying. Patients are often "scrambled and distressed," and as a result have poor recall of what is being said within any given consultation. The psychologist wants to support them as best she can, to take a part in the "play" that is the dynamic of clinic life. She uses this analogy to encourage patients to address risk appropriately, to use the expertise of all the players involved, and to consider who might be the most relevant team member, at any given time, to support them. "Different people take different parts on stage at different times." The psychologist has to manage patient anxiety, while helping patients contain their emotions and overcome their worst fears. She is there to uphold confidences, and above all else, not let the patient get too disillusioned with their treatment, or the team's response to treatment outcomes. "We all want certainty in an uncertain world," but information needs to be provided sparingly, in order for patients to realign their goals to reality. "We have a gentler way of doing risk assessment," in order to: "talk about risk of values not being met." This is at the crux of the psychologist's role, to steer the patient, carefully and empathically, through a maze of

(continued)

emotions and moods, and subtly help facilitate discussions with oncologists that are going to encourage patients to be realistic in the face of a very daunting disease.

Example 2 of an Individual Schema

Chloe saw herself as an intermediary between patients and the medical system. She interprets doctors' messages for patients: not just medical information on tumor and their treatment progress, but the elephant in the room about the key question of short- and long-term survival. "Whether they're going to die" is an often unspoken, yet most important question for patients in the complex and traumatic journey of cancer treatment. Chloe works closely with patients to help them navigate the medical complexities of treatment, communication challenges with oncologists, and the healthcare system. Chloe recognizes that the cancer care system is responsible for some uncertainty and inconsistency in patient care. Firstly, there are variations between healthcare professionals' practices. Different doctors talk about, and emphasize, different types of risks: "surgeons are more likely to use numbers and talk about risks of surgery, complications and side effects; palliative care doctors focus on goals of care," and the way they communicate to patients is different as they: "vary in skills, vary between teams, and in seniority." Secondly, the treatment journey is full of different types of risks: tumor risk, treatment risk, as well as emotional, financial, and psychosocial risk. Even in posttreatment survivorship, patients are faced with the risk of recurrence, posttreatment medication side effects, and posttreatment trauma. Thirdly, each patient will vary in their emotional response to cancer diagnosis and treatment; where some are more emotionally vulnerable, others are less so.

Chloe's role is to assist patients in managing the range of anxieties and fear that may arise as they face these complex uncertainties. Chloe saw her role as helping patients gain: "certainty in an uncertain world", so that they can cope with the grueling process of treatment and enable the medical team to do their job: "my whole role is to make sure [patients] keep confidence in the medical team." She recognizes that face-value reassurance does not reflect the reality of dealing with the trauma of disease. For example, doctors are hesitant to be frank to a patient who is emotionally vulnerable: "there is an agreement within the team to keep information limited, because if we convey exact risk, she won't cope." Clearly, for Chloe, psychosocial risk will impact on medical risk, and thus her role as an intermediary between doctors and patients is to manage a balance between these two. As a psychologist, Chloe's expertise is to help patients bring medical facts into line with their personal values: "we talk about risks of values not being met" and her role is to help patients: "get a more realistic idea about their risk."

4.2 Stage 2: The Group or Meta-schema

Following the initial workshop, Stage 2 was planned. The team met on an ongoing basis to agree on the most essential elements of the individual schemas, acting as an interpretive community.

During Stage 2, an important aspect of the group work was to meld understanding. For the purpose of this study, understanding revolved around how Chloe described her consultations with breast cancer patients, her experience of these consultations, and her presentations of “risk” to patients. The team also examined how the implications of being part of a multidisciplinary team in this context impacted on patient-professional interactions.

As mentioned earlier, essential elements drive greater clarity through the schematic process. They highlight integral pathways through conversations and biographic insights, and they lead to a greater team awareness and commitment. They suggest the participant’s point of view, but by so doing, draw the co-researchers together, to take shared ownership of re-presenting that point of view. They indicate a story yet at the same time offer vital insights into self-expression and all from the perspective of the research participant.

Example 3 of a Group Schema

As a psychologist, Chloe has an intermediary role in interpreting medical information provided by the clinician and sharing it with the patient, while guiding patients along an appropriate care pathway. She is there to offer patients a route through the medical system while helping them gain more certainty in their lives. Patients’ personalities, their circumstances, and life experiences are so different, and so are their responses to a cancer diagnosis. One of Chloe’s key roles is to help patients manage the range and fluctuation of their fears and other emotions associated with cancer diagnosis and treatment. By “providing certainty in an uncertain world,” Chloe can help patients maintain confidence in the medical team. This is crucial for successful treatment as well as for the ability to manage patients’ anxieties. Chloe’s conversations with patients are gentler in approach than those of her peers. Her discussions add nuance to medical representations of risk in a way that is more aligned with patients’ own personal goals and values. This can encourage patients to be more realistic in their understanding of risk when in discussion about treatment with oncologists. As a psychologist, Chloe angles her conversations with patients towards three things: (1) the patient’s prognosis, (2) patient drivers, e.g., their fears, values, and goals, and (3) doctors’ drivers, e.g., what the doctors would like the psychologist to help them achieve, e.g., Psychological readiness for treatment and for receiving challenging information.

Coming to recognize the essential elements of any text is a road to team discovery, and following listing and labeling (including key quotations presented verbatim) in the case of the exemplar study, the group were able to redefine their

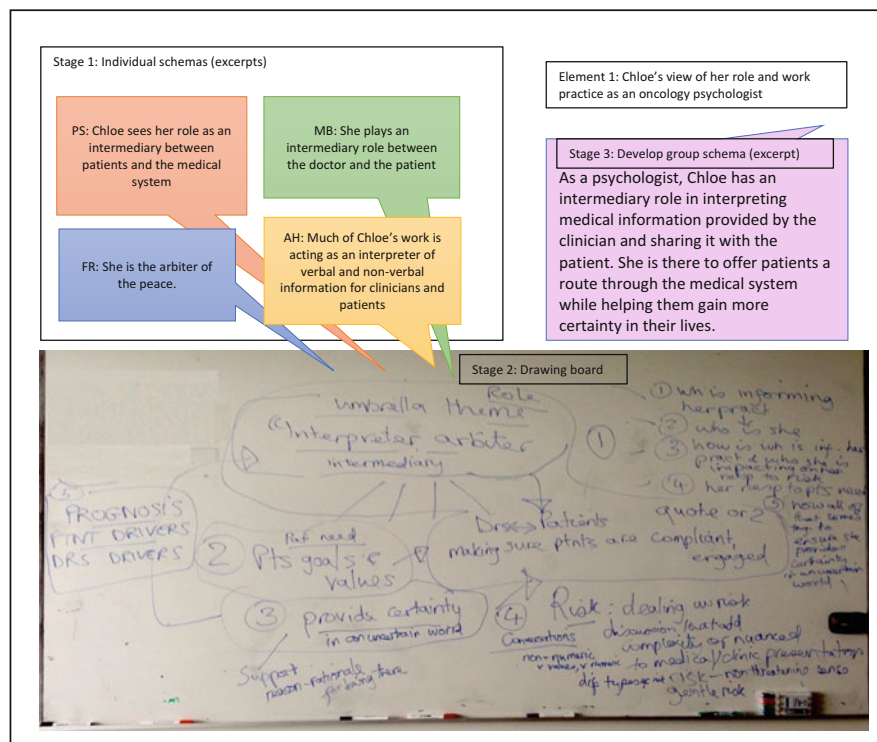


Fig. 3 Developing a part of the group schema for Element 1 (Chloe's view of her role and work in oncology psychologist)

individual schemas as one meta-schema that retold the story, succinctly and clearly (see Example 3 for detail of this group's example).

The Teamwork Drawing Board in the center of Fig. 3 demonstrates the development of five core elements that needed to be presented in the meta-schema, derived, in this instance, to explicate the interviewee's view of her role and working practices as a psychologist within an oncology multidisciplinary team, and the elements were:

Element 1: Psychologist as interpreter, intermediary, and arbitrator between clinicians and patients.

Element 2: Psychologist as identifier with patients' goals and values.

Element 3: Psychologist as provider of a sense of certainty in an uncertain world.

Element 4: Psychologist as expert, presenting "risk" to patients in a nuanced and person-oriented way.

Element 5: Work practices are grounded in the patients' prognoses, patient drivers (e.g., their fears, values, goals), and clinicians' drivers (e.g., ensuring patients are psychologically prepared for certain treatment decisions or for receiving challenging information).

These five elements were developed by using, as a core to their meta-presentation, the ideas generated from each person's individual schema. The following section

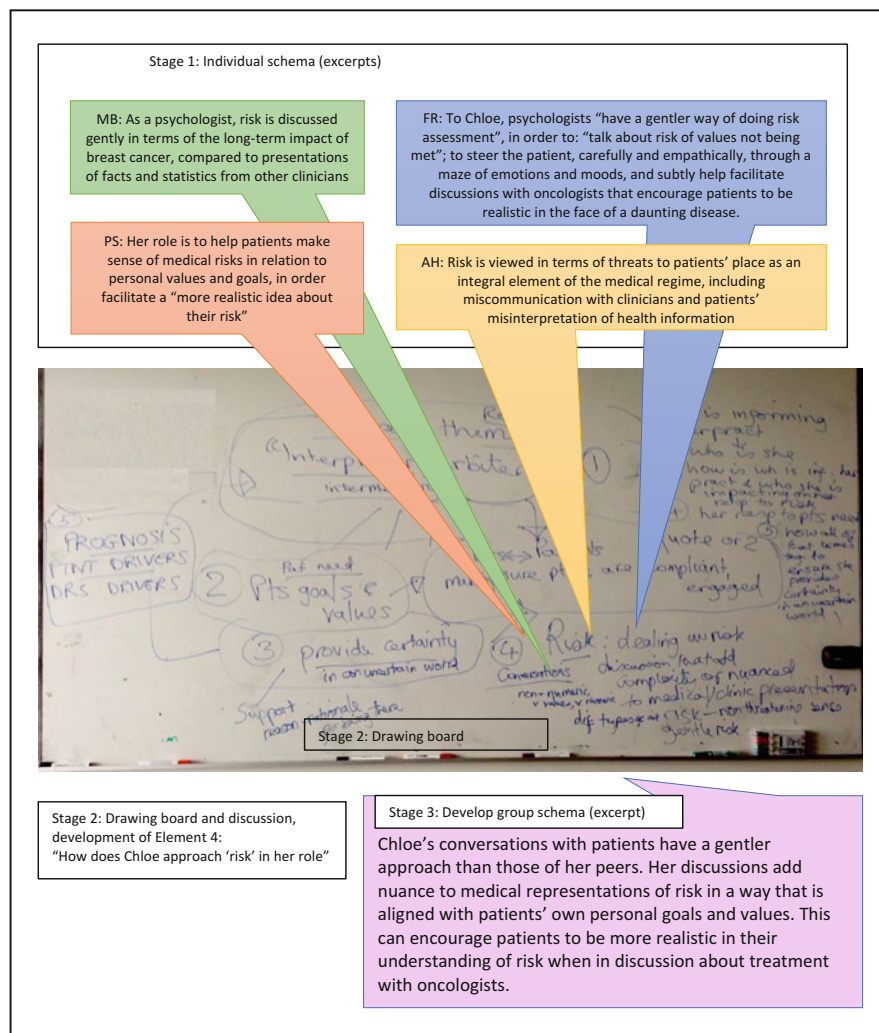


Fig. 4 Developing a part of the group schema relating to Element 4 (“How does Chloe approach ‘risk’ in her role?”)

explains how some of the elements were analyzed. For example, Element 1 came from the general consensus (Fig. 3) that as the interviewee was acting as an intermediary between patients and clinicians, she was frequently presenting each party’s goals and objectives to the other party.

Element 4, on the other hand, was developed from a more nuanced discussion about what “risk” might mean to the psychologist working with patients in these circumstances, and the different types of risk the psychologist might need to deal with, as well as how this has impacted on her descriptions of her work and approach to patients (Fig. 4). Through discussion and some ongoing debate, the group schema

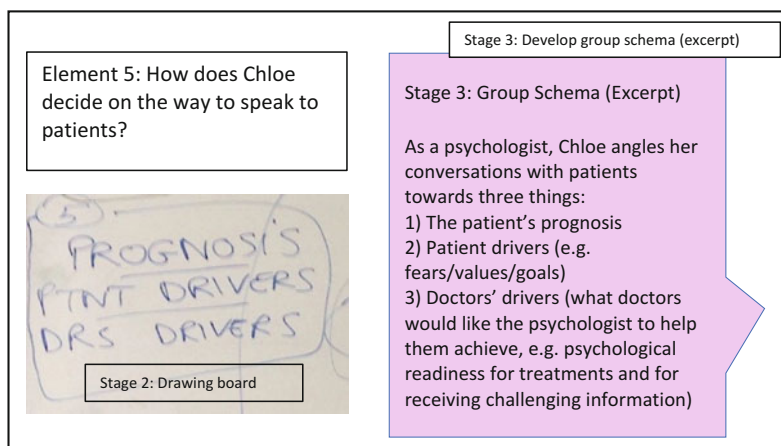


Fig. 5 Developing a group schema to include Element 5 (“How does Chloe decide on the way to speak to patients”)

included Chloe’s understanding of risk from the point of view of her role as a psychologist and the effect this has on the way she approached the topic of “risk” with her patients.

Element 5 arose from group discussions of the elements embedded in the individual schemas and the group’s subsequent understanding of the way Chloe used her own response to risk, and her role as a psychologist, to inform her professional practice (Fig. 5).

4.3 Stage 3: Interpretation of Meta-schema

Once Stage 2 was completed, the team felt at liberty, for the first time in the analytic process, to consider the meaning underlying the meta-schema and to discuss what the meta-schema led the group to conclude. The interpretative stage, or Stage 3, enabled the researchers to examine why the situation was as it was and why a view was expressed in a certain way or a relationship created with others. Stage 3 unfolded in line with the literature on the topic and others’ appreciation of the topic and its current relevance. Interpretations were revealed once the meta-schema was crafted, and it was kept intact and shared alongside the interpretation of its contents, line by line. This encouraged the whole team to reflect back upon the raw material and ensure nothing of importance had been left out. Verbatim quotations embedded in the meta-schema gave the piece its flow and direction, but also helped give weight to the research team’s views of the most important points spoken by the participant, with the participant’s voice clearly present. Understanding was embellished by consideration of other participant transcripts and observational field notes. On this occasion, field notes were used corroboratively, to highlight dynamic moments in patients’

consultations, the way people interacted in the consultation, and to add to the veracity of the schema analysis method, by providing additional and contextual information to support schema findings.

5 Validity, Rigor, and Trustworthiness of Data

Validity of data, in this case, refers to the ability of data to be seen as sound, reasonable, and credible and presented in such a way that accurately represents Chloe's views. Validity also suggests that the study's conclusions link back to the raw material and thus convincingly achieve meaningful findings.

The core techniques of schema analysis, group-working, checking and rechecking of data, and the development of individual and meta-schemas, lend itself to an accurate and thorough representation of the raw material through consensus-building activities (Thomas and Magilvy 2011). This adds to the credibility of data and the knowledge that the process can be replicated by another research group to generate similar results (Thomas and Magilvy 2011). The group work discussion adds rigor to the working methods (Long and Johnson 2000), and the engagement of multiple researchers counteracts any one individual having excessive influence over the production of study results.

Trustworthiness of data consists of four components: credibility, transferability, dependability, and confirmability (Lincoln and Guba 1986). In schema analysis, credibility is assured when multiple researchers agree that the data analysis aligns with the reality of the original texts. Using group consensus, when the group arrive at a position that the emergent schemas are uncontested, and study findings are representative of the participants' views, it can be said that data are credible. Transferability is assured during the interpretation phase, when the contextualization of data reveals how meta-schema can be applied to other situations and settings. The dependability of data can be assured when others can repeat the data analysis process, if desired, with a different group of researchers, arriving at the same or similar conclusion, regardless of who is involved. Confirmability ensures that the study's findings are robust. The teamwork aspect of schema analysis enables key findings within meta-schemas to be conferred across analysts (see also ► Chap. 63, "Mind Maps in Qualitative Research").

The final stage of the process, the interpretation stage, ensures that no one component of data is prioritized, before wholistic descriptions of all data are produced (Lincoln and Guba 1986).

6 Lessons Learned: Enriching Qualitative Analytic Practices

The degree of difference between schema analysis and other qualitative methods becomes apparent as researchers immerse themselves in this new approach, and there are distinct methodological and practical strengths and weaknesses in representing and interpreting complex datasets in this way.

Strengths: Firstly, in terms of the method's strengths, schema analysis arises from a *process* of representation, collation and interpretation, and extensive researcher collaboration. Secondly, individual aspects of the method ensure a deep grounding in the data without the influence of others: ("This is my understanding of what X is saying about herself") before group understanding is sought. Thirdly, each researcher is encouraged to "get inside the participant's head" and engender, in their individual schema, a strong representation of the person's voice, lending itself to a person-centered approach to analysis. Fourthly, once individual schemas are considered by the team, similarities and differences between them become the salient points for discussion, and learning occurs as a team. The collaboration needed to refine individual representations into a group representation, which embodies a shared understanding of the data and a collaborative representation of the participant voice, ensures clear agreement across group members, adding veracity to the value of group-working. Fifthly, a mentoring process can be built into the schema analysis, with more junior researchers or those less familiar with qualitative methods learning the techniques from the active modeling of others. The value of this is that ongoing reflective discourse between researchers results in a more cohesive and rigorous analysis, with equal buy-in from all researchers. Finally, as each member of the team has the same amount of work, tasks cannot be delegated or parceled out to others, suggesting equal commitment to the process at hand.

Weaknesses: Firstly, if the precise steps of the process are not followed, the schema produced will be inadequate. Secondly, researchers must resist the temptation of interpreting data preemptively. Thirdly, removing one's researcher perspective or clinical self from the representation can be difficult, but failure to do so can result in a flawed representation of the participant's point of view. Fourthly, team members must refrain from sharing their own opinions too readily, but equally must be sure not to omit their opinions at the interpretation stage: ("It's not about me").

Combined strengths and weaknesses: Generating schemas takes time. Group schemas rely on the availability and cooperation of all workshop members, and as meta-schemas are based on more than one representation, the process can be disadvantageous to a researcher wishing to work alone. While schemas can be developed and then analyzed by individual researchers, there is no in-built mechanism to check the quality of representation of the participant voice and no capacity to develop a collaborative group schema. While the team approach to analysis is a resounding strength, methodologically, it is also a weakness of practicability.

7 Conclusion and Future Directions

Since its first development, schema analysis has been used extensively by the authors to make sense of complex data across health service and medical research contexts. For example, it has been successfully applied to assess breast cancer patients' responses to decision aids for treatment and care (Rapport et al. 2006; Iredale et al. 2008). It has been used to clarify multidisciplinary team practices for assessment of breast cancer risk (Shih et al. [under review](#)), and it has helped examine

differences between communication styles in individual breast cancer consultations and multidisciplinary care (Rapport 2010; Rapport et al. 2015). Schema analysis is currently being used to underpin a study assessing cochlear implants for use by older Australians to improve hearing health and reduce listening effort (Rapport et al. [under review](#)).

Schema analysis has the potential for broader application than this and may be highly applicable to research that requires an in-depth understanding of a particular client group. For example, it could be useful in diverse fields such as business, education, and the environmental sciences where a strong interest has grown in the needs of stakeholders to drive and give meaning to a system, in order to deepen understanding of clients' needs and experiences and ensure improvement in these fields is in keeping with client expectation. With versatility and flexibility built into the method, and a growing interest in it as a very practical approach to team-building and team awareness, the potential of this method, as it continues to be refined, is extensive. We urge others to try it out for themselves, to assess its value in their own research studies, and to experiment with its application across human and health science domains and topic areas.

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Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses

52

Pat Bazeley

Contents

1	Introduction	918
2	Establishing the Goals of Analysis	919
3	Selecting Data for Analysis	921
4	Managing Data for Analysis	922
5	Reviewing and Exploring Data	924
6	Sorting and Coding Data: What Are My Data About?	926
7	Investigate and Interrogate	931
8	Conclusion and Future Directions	933
	References	934

Abstract

Qualitative data analysis software (QDAS) has much to offer the health researcher. Software facilitates efficient management of qualitative and mixed methods data through a variety of tools to organize and keep track of multiple data sources and types and of the ideas flowing from those data. Coding tools provide structure to the categories and themes evidenced in the data, allowing for rapid retrieval of information. Increased depth and rigor of analysis are facilitated through capacity to search and interrogate the data sources using a combination of coding and other data management tools. Questions can be asked about how often and how different categories or themes are expressed by different groups within a sample or within different contexts or times. Similarly, experiential data might be compared for those with different measures on health-related variables. Relationships between different aspects of experience (or attitudes or feelings, etc.) can be explored and/or verified using coding queries, through a range of visual displays,

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917

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or through statistical analyses using exported coding information. Such queries can be limited to one type of data, or multiple types of sources can be imported, coded, and analyzed together. Linking tools are used throughout to connect reflective thoughts to the data that prompted them or interim results to the evidence that supports them. Explanations of these processes are illustrated by figures and examples.

Keywords

Qualitative · Software · Analysis · Mixed methods · Coding · Visualizing · Theory building

1 Introduction

Various forms of software to support qualitative data analysis were developed for public use in the 1980s and 1990s. These software developments followed closely on the rapid developments that occurred in the use of qualitative approaches to research that began a decade earlier and were supported by the revolution occurring in computer science with the shift from mainframe to personal computers. While statistical software to analyze numeric data was widely adopted without question in the quantitatively dominated research climate that prevailed at the beginning of the digital era, adoption of qualitative software as a legitimate tool to assist analysis of textual data has been a much slower process – and continues to be resisted in some quarters. The majority of early programs focused on “code and retrieve” as a primary tool to assist analysis, because this is what computers were good at doing. The capacity to query connections in coding was also there as an extension to code retrieval but was often ignored. This was partly because querying required a higher level of technical skill in the user, but also for some, the use of logic-based queries was (and is) seen as a poor substitute for the “intuitive” connections arising from deep immersion in data, manifested in the work of skilled qualitative researchers. Qualitative software, in its current form, is a product of the developments that have taken place in both computer technology and methodology in the twenty-first century; it provides a much wider and ever-expanding range of tools to emulate the tasks involved in qualitative analysis, yet its heritage in those early 1980s developments, with their emphasis on coding as a primary analytical task, is still very much evident.

One of the issues faced by developers of software for qualitative analysis was, and is, the diversity of qualitative methodologies and the inherent complexity of the analytic and interpretive processes associated with those methodologies – processes that are not readily reduced to linear algorithms, such as occurred with statistical analyses. This complexity requires flexibility in the way software tools function, which in turn engenders complexity in software design – and for the user, a relatively steep “learning curve” to achieve effective use of the software for her particular purposes (Gilbert 2002). This further inhibits adoption by some researchers using

qualitative methods. Nevertheless, adoption is now widespread, and the use of software for analysis of text and visual data is becoming more or less expected in many fields.

Just as the qualitative “revolution” challenged and changed foundations for research from the 1970s, so also a mixed methods revolution has been changing research practices, primarily since the 2000s (Mertens et al. 2016). There has been some adaptation in statistical software, but it is qualitative software that is really taking up the challenge of developing ways to merge quantitative and qualitative data and analyses. Further challenges in a digital era of big data and social media are being met by both statistical and qualitative analysis programs. Software of both types is constantly evolving, as developers work to meet the rapidly evolving landscape of research methods in a digital age.

Although technology plays an increasingly important role in the health sciences, health is essentially about human populations and the individuals that make up those populations, with all of their physical, mental, emotional, and spiritual qualities (Huber et al. 2011; Liamputtong *in press*). Used wisely and with sensitivity, qualitative data analysis software (QDAS) can assist health researchers in their work, insofar as it is focused on the human interface of health care. It does so by offering a flexible suite of tools to use in managing and working through qualitative (and mixed methods) data, aiding analysis and interpretation in the process. Users of QDAS find coding, memoing, linking, querying, and visualization tools that help them to work with, reflect on, and see their data in new ways. It can assist, but not substitute, for deep immersion in data and the skilled recognition and interpretation of linkages and patterns across data by the researcher that are the hallmarks of ground-breaking qualitative analysis. Additionally, the use of software ensures more systematic and transparent analytic processes, with conclusions not only supported by evidence but by evidence and a chain of thinking that can be traced. Ultimately, however, the analytic interpretation remains in the researcher’s skilled hands.

Software is often dismissed as something that is useful only at the latter stages of a project, when analysis is in full swing. I propose in this chapter to take the reader through the main stages of conducting a research project and to demonstrate that QDAS has a role to play from start to finish.

2 Establishing the Goals of Analysis

If we are to consider how software can assist health researchers achieve their goals for analysis, a first step must be to establish what those goals might be. And immediately one is faced with the diversity of health research, just as health care and health services are diverse – a reflection of the breadth of what health itself entails. Research goals can range from the conceptual to the practical, from measurement-oriented assessment of the benefit of a drug or surgical intervention through to exploring the phenomenological nature of particular health-related

experiences (which might, coincidentally, be of drug or surgical intervention), and from a focus on policies, organizations, and services to a focus on ordinary people and their daily lives.

The role (and value) of software for analysis has its starting point right here, at the point of establishing goals for analysis. What will this project be designed to achieve? What, and whose, purposes will it serve? QDAS contributes in three ways at this pre-analytical point: through recording reflections, mapping preliminary ideas, and reviewing and analyzing literature.

Keeping a record within the software of one's musings over purposes and goals is helpful insofar as the act of writing assists in building clarification. Having a written journal recording ideas and steps taken additionally provides the basis for an audit trail relating to project development, something that becomes useful when justifying choices made and explaining directions taken, during a later stage of reporting. Applying some codes to this document as it is being written assists during analysis and writing with locating particular ideas, and it generates starter codes to apply to literature or participant data. For those new to QDAS, this provides a gentle introduction to using software.

Modeling (mind-mapping) ideas about the topic being studied also helps in clarifying those ideas, and with project planning, by pointing to those things for which data will be needed (see also ► [Chap. 63, "Mind Maps in Qualitative Research"](#)). Items entered in a mind map or conceptual model become represented as codes that will capture data and links drawn between items in an early conceptual model become assumptions to test (Fig. 1). Ideas sparked through mapping processes are recorded in the project journal, again assisting clarification and for later reference.

Most researchers now use bibliographic software to manage the literature relating to their research. That literature can be selectively imported from the bibliographic tool into the qualitative software, with abstracts, notes, metadata, and, where available, the original .pdf sources. Once imported, those materials can be coded interactively or searched using selected terms to identify relevant passages for consideration (rather than a search simply identifying whole references, as occurs within the bibliographic software). Alternatively, the content of articles might be rapidly scanned, aided by predictive auto coding tools that are available to varying degrees in different qualitative programs. Working through the literature on a subject is, of course, a key tool for refining objectives for the research and for identifying concepts and frameworks that, in turn, become tools to guide both design and analysis. When literature is incorporated into a project file, passages within it can be linked to new data, contributing to building a connected web of knowledge. Alternatively, queries can be used to compare what is being revealed through this project with established understanding as expressed in the literature. For example, professional understanding of caregiving for an aged person as a set of instrumental tasks is inconsistent with families' perceptions of caregiving as something more akin to psychosocial care; similarly discharge planners' views of home care needs can be very different from patients' perceptions of home care needs, with such inconsistencies leading to problems of noncompliance (Bowers 1989). (Coding and querying processes will be explained below.)

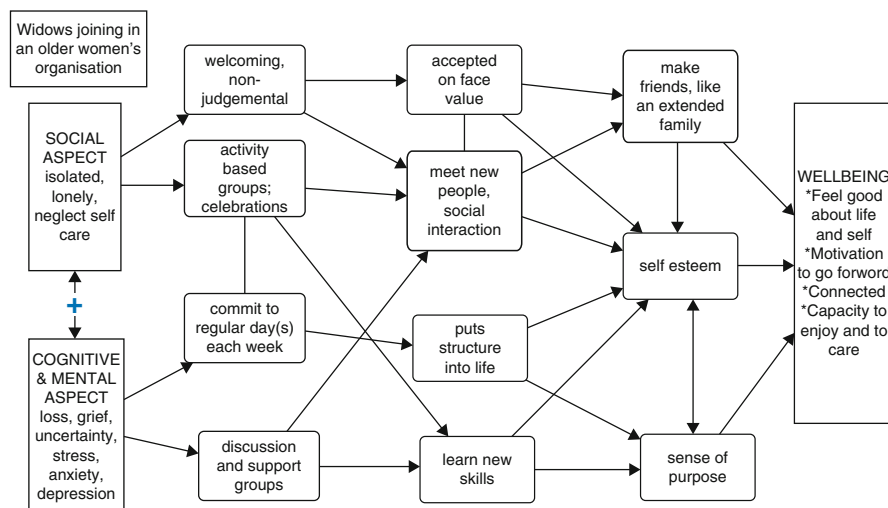


Fig. 1 Conceptual model: how older women's groups benefit the social and mental well-being of widows

3 Selecting Data for Analysis

Traditionally, qualitative health researchers have relied heavily on interviews or, to a lesser extent, focus groups to provide research data. Diaries, journals, and observations also provide data for some, while visual data (video, images, drawings) and documents (e.g., medical records, nursing notes) offer less frequently accessed forms of qualitative data. Researchers are also exploring the potential of network, geographic, and social media sources (see chapters in the "Innovative Research Methods in Health Social Sciences" section). Health services and evaluation researchers taking a more quantitative or mixed orientation have relied largely on surveys and questionnaires, sometimes including some open-ended questions within those (see ► Chaps. 20, "Evaluation Research in Public Health," and ► 32, "Traditional Survey and Questionnaire Platforms"). Increasingly, health researchers are broadening their traditional methodological approaches to combine these multiple sources and types of data, in what has become known as multimethod or mixed methods research (see chapters in the ► Chaps. 39, "Integrated Methods in Research," ► 40, "The Use of Mixed Methods in Research," ► 41, "The Delphi Technique," ► 42, "Consensus Methods: Nominal Group Technique," ► 43, "Jumping the Methodological Fence: Q Methodology," ► 44, "Social Network Research," ► 45, "Meta-Synthesis of Qualitative Research," and ► 46, "Conducting a Systematic Review: A Practical Guide" section).

Relatively recent developments in QDAS ensure that almost any type of data can find a place in a project managed using software. As well as text data, most programs allow for importing video and image data in a variety of formats, several allow for

recording geocodes (e.g., manually, or from GPS) and for displaying these in map format, some for incorporating geographic images as a base on which to “map” other visually displayed qualitative data, and some now facilitate importing information directly from websites and/or social media platforms (including associated meta-data). Additionally, survey data that includes open-ended responses can be imported directly from either Excel or online databases such as SurveyMonkey or Qualtrics. Basic demographic data for participants has always been considered useful in qualitative projects; in mixed methods projects, this is likely to be extended to include categorical responses and scaled data. QDAS usually deals with this demographic information and also any other quantitative variable data relating to participants or cases in the research by treating it as variable or attribute data which is then associated with related non-numeric data for those participants or cases. Finally, for those using ethnographic or other methods where data are continually added to ongoing field notes, records can be created and maintained within the software.

4 Managing Data for Analysis

Data management is rarely discussed in texts, and yet it is a crucial element in analysis, especially for the complex kinds of data that might be part of a qualitative project or a mixed methods project. Miles and Huberman (1994, p. 43) observed that “qualitative studies, especially those done by the lone researcher or the novice graduate student, are notorious for their vulnerability to poor study management.” Approaches to and requirements for data management should be considered *before* data are gathered for a study, because these can impact on what can be done with those data during analysis – how they can be sorted, compared, and queried (Bazeley 2013). In particular, some forms of data (e.g., focus group data, survey data) require special preparation to access the features of software that facilitate linking demographic, categorical, and scaled data with qualitative case data (Bazeley and Jackson 2013).

Being able to trace and identify the source of evidence used, as well as the context for that evidence, is important for the transparency and transferability of results. Keeping track of sources, and of segments of data from those sources, during the process of coding and analysis is facilitated in QDAS through the use of folders, descriptions, and labeling (Fig. 2). Different kinds of sources are placed into folders or document groups, so that it becomes easier to see what data are available within the project. Contextual and reference information about specific sources can be recorded in descriptions, linked memos (a good place for associated field notes), or in associated variable data. And, whenever a particular segment of data is retrieved, the software indicates the source of that segment and provides the option to link directly from the segment back into its original context to assist in its interpretation (Fig. 2).

Managing sources in a way that allows for their analysis both as separate entities *and* as a common body of knowledge has always been a problem for qualitative researchers dealing with voluminous and messy data. QDAS assists this process by

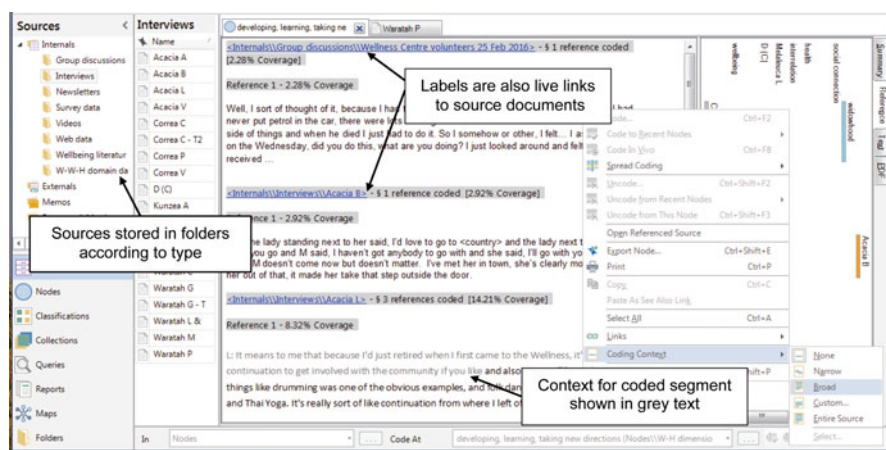


Fig. 2 Keeping track of sources and context for coded segments

providing multiple systems for sorting and “cutting” data, in ways that facilitate both targeted and comparative analyses.

Folders used for sorting and viewing sources become useful at the analysis stage as well. Some types of analyses are more or less appropriate with specific kinds of data, and so folders allow for scoping (focusing) a query to a specific group of sources.

Qualitative and mixed research projects are often structured around *cases* – the participants or other entities that exemplify the phenomenon being studied (Bazeley 2013; Yin 2014). NVivo facilitates the development of a dedicated structure for holding together diverse sources of data about each of the cases – the units of analysis – in a project, thus facilitating case-based analyses. Data for each case are *coded* to specifically designated categories, which means that data relating to a particular case can include one or multiple sources of the same or different types, and/or parts of sources. Thus, a participant’s case data might include a combination of interviews along with their contribution to a focus group and their contributions to a meeting as discerned from the minutes of the meeting. In addition, attribute data (demographic, categorical, or scaled variables) relating to the case would be entered or imported and attached to that case’s code, which means it is automatically applied to all data coded to that case, even if added later. Attribute values can then be used as a basis for comparative analyses (as described in a later section). The alternative, for QDAS that do not offer a specialized case structure option, is to use the general coding structure to create a parent code for cases with a set of subcodes. Each subcode would then represent a case to which all relevant material is coded. In this situation, however, attribute (variable) data can be attached only to whole sources.

Sets are created in QDAS to hold together aliases for collections of sources, or of codes (or in NVivo, also a combination of sources and codes). Aliases update as the

Fig. 3 Using data management tools to support a complex comparative query

	Time 1	Time 2	Time 3
Child			
Mother	Data in cells is scoped to include only text/data segments coded <i>anxiety</i> .		
Father			
Doctor			

material they represent is updated. Sets are useful, for example, for separating sources created in different phases of a longitudinal data collection (Time₁ . . . Time_n), or for designating different categories of contributors to a set of cases (e.g., when interviews are held with mothers, fathers, doctors, and the target child for each child [the case] with juvenile diabetes). Making sets of codes can be a useful strategy for identifying concepts that “hang together,” perhaps making for a more comprehensive or abstract category. The particular value of sets in analyses is that the software will treat the contents of a set as a single item, facilitating their use in comparative queries, or again, for scoping queries to a particular set of data.

Using these structural tools in combination will allow, for example, for a comparison of what different people [identified by sets] had to say about the anxiety [achieved by scoping the query to a particular code] over time [identified by sets] for children with juvenile diabetes [the cases] (Fig. 3). Or, the anxiety [code used for scoping the query] of specific children [cases] or groups of children [identified using attribute values] might be compared over time (sets), based on the combined input of those who are connected to each case.

While folders, cases, and sets can be set up at any stage during a project, it is nevertheless important to have considered what they might look like at the start of data collection, especially where these impinge on the way data are prepared (what formatting is required) and how they are labeled. Good management facilitates good analysis; it also prompts the qualitative researcher toward clarity and transparency, with potential impacts for ongoing design as well as analysis.

5 Reviewing and Exploring Data

Simply reviewing and/or exploring each data item as it is gathered is traditionally recommended as a first step in qualitative analysis (Bazeley 2013; Liamputtong and Serry 2017). In the early stages of a project, it can be found necessary to make adjustments to data collection procedures, based on these early reviews. Reviewing the whole of a source again, before detailed work is begun, helps to ensure specific elements within the source will be seen in the context of that whole. Many researchers prefer to read through and annotate a paper copy at this stage, although using software to add notes on or linked to specific points while reading through is not only possible but has the advantage that those initial impressions are not lost to later analysis. Some also find it helpful to summarize the key points learned from a

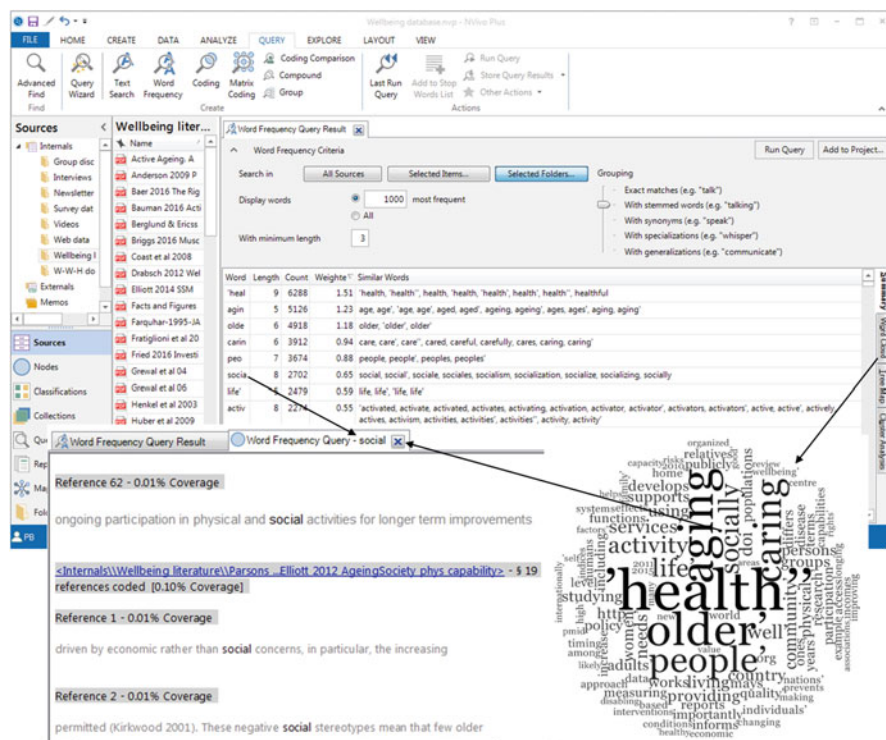


Fig. 4 Word frequency query with links to associated text

new data source; these can be recorded in a memo linked to that source. Another alternative is to use the mapping tools in software to create a visual diagram representing the narrative or perhaps the interconnected ideas being gleaned from the data source during this exploratory phase.

Of course, not all projects have data coming in one piece at a time, to allow the kind of work just described. Qualitative data can come in larger volumes, especially when sources other than interviews are being used. It is still valuable, however, to obtain an overview of what these new data are saying, before delving into detail. For this task, QDAS offers the options of either a global word frequency count or targeted word searches. A word frequency count will identify the most commonly occurring words – the overview – and present these as a summary or in a visual display. Each line in the summary then provides a direct link from the listed word to the passages where it was found, and from there to the broader context of that find (e.g., the paragraph in which it appeared), or to the source documents, allowing for a deeper exploration of any words of interest, and the concepts they represent. These strategies are useful, also, for scanning the literature, as shown in Fig. 4.

Recording ideas as they occur and reflecting on what is being learned are useful at any stage of the analysis process, and this time of initial review and exploration is a good time to establish lasting habits for doing so. Ideas and reflections can be

recorded either in a general journal for the project or in memos linked to specific sources – the choice depends on what is being recorded about what (e.g., insights about the project as a whole, or its methodology, or reflections about the particular source). In the process of writing these reflections (of either kind), it is useful to link them to the source text or items that prompted them. In NVivo, a specific segment of data (or literature) that prompts an analytic or reflective thought is copied and pasted *as a link* within the journal or memo document at the point where the reflection is written. When the link is activated, it takes the researcher back to the copied evidence, showing it in its original context. In MAXQDA, separate memos for each passage are attached directly to the paragraph containing the passage that prompts the reflection; thus both programs achieve the same goal of connecting reflective thoughts to the evidence that supports them. Similarly, connections can be recorded linking from text (or other detail) in one item to text (or other detail) in another (e.g., from a data item to relevant literature; from one reference to another; from part of a picture or video to a discussion about that component or event).

Journal or memo entries are optionally coded to categories used also for coding data. This has the benefit of allowing the researcher to easily retrieve not only data on a particular topic but also reflections on that topic, potentially with links back to source data that provided the basis for the reflections. It overcomes any problems of trying to remember whether that note was made in the project journal or a particular memo.

Decisions made about the way the research is being conducted and about the direction of the analysis are also usefully recorded throughout the project (applying time stamps to these entries is a good idea). Some researchers choose to record these methodological steps in a separate journal; others use the general project journal. This builds an “audit trail” for the project – a record that explains what was done and why it was done that way (Carcary 2009; Richards 2014; see also ► Chap. 63, “Mind Maps in Qualitative Research”). This will help the researcher show the pathway taken in reaching the project’s results and conclusions and allows for a more transparent write-up, for the benefit of the eventual readers.

6 Sorting and Coding Data: What Are My Data About?

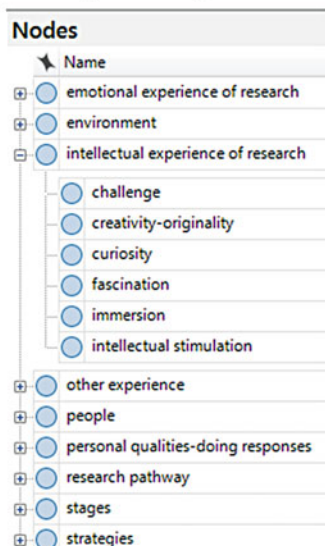
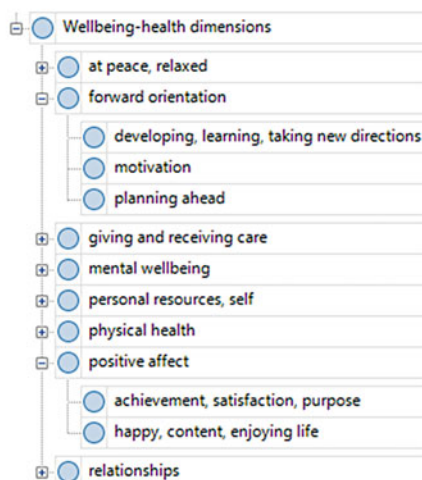
As much as making connections between data items, the ideas in those data items are an important aspect of qualitative analysis, and there is no question that coding is the basic tool that underpins most forms of qualitative analysis (Strauss 1987). Coding is essentially a form of indexing that allows the researcher to find all the passages in their sources that relate to a particular topic, with the topic being represented by a label (the name for the code; see ► Chap. 48, “Thematic Analysis”). Coding, therefore, is an analytic task that connects data to ideas; it requires a level of interpretation by the person applying the codes (Bazeley 2013). During the coding process, the researcher is also making connections between those ideas (these should be noted in the journal, to be further explored). Codes might be topic-based, contextual, or more abstract and conceptual. One of the simplest ways to move

from descriptive coding to more abstract coding is to keep asking “Why am I interested in that?” (Richards 2014). The codes developed in this way have significance beyond the immediate source, making them more analytically useful, although more descriptive codes retain their value also in recontextualizing more abstract concepts.

When coding was done manually, researchers would either write labels in the margin next to relevant passages, make copies of their documents, and then cut them into sections that were then sorted into piles for each code or create index cards that listed where relevant passages could be found, with a summary of what was in those passages. All of these methods imposed limitations on the researcher, either in terms of retrieving all that could be known about a particular topic or, more particularly, in sorting and connecting passages to explore or demonstrate a relationship between codes (e.g., a patient’s mood when at work, compared with his mood at home; or, to identify the nature of a child’s response to bullying at school, and then the impact of this on their sibling relationships). Because manual coding systems tend to limit the level of detail one can build into a coding system, they foster the use of more global codes in order to capture all of what is happening in a passage in one code, with a consequent tendency to rely on simple thematic analysis.

Coding with QDAS involves selecting passages and identifying what that passage is about. Each element of what is “going on” in a passage is captured with separate codes, and each code represents a single concept. Thus, responses or actions that signify improvement in, say, a medical condition might be coded for the type of response and/or action, descriptively for the particular condition being referred to and for the circumstances where the improvement became evident, as well as for the more abstract category of “improvement in condition,” with each of these aspects being picked up by different codes and applied to the same passage of text. This has two consequences: firstly, all material relating to any particular code can be readily retrieved (with the source identified and accessible for each retrieved passage), allowing the researcher to explore in some depth what that concept is about – to see data in terms of the category rather than the original sources; and secondly, connections between codes, in terms of passages that are coded by particular combinations of codes, can be readily found using the query functions in the software. This means, for example, that the connection between a “what” and a “how” can always be reestablished, such as how and where improvement were demonstrated, with relevant passages retrieved. More than that, however, connections between the same “what” and different “hows” can also be explored. Thus, using the examples given above, if codes for where a mood is being experienced are applied at the same time as codes for the type of mood being experienced, the software can sort out text to illustrate and compare which moods are being experienced where. Or, text about a child’s response to a bullying experience can be associated with that child’s way of interacting with siblings, and perhaps also with responses, say, for children living in different family circumstances being compared.

The way in which a QDAS coding system is structured has implications for how well a researcher can use the codes to explore and interrogate her data. The most effective coding systems, in terms of facilitating querying, are those that categorize

Becoming and being a researcher**Dimensions of wellbeing for older women
(one tree within a more extensive coding structure)****Fig. 5** Sample coding structures for two projects

codes by what kind of thing they are about, in a taxonomic system (rather like the way plants are categorized), that is, its branching structure is not theoretically determined. Thus, for example, different events will be listed as subcodes within one “tree,” emotions will be listed in another, as will times, places, or who is involved in particular events or emotions, or whatever else is being coded (Fig. 5 shows partially expanded examples for two projects). In an analytical sense, it means that any code can be associated with any other code, without limitations, with queries being able to find particular links as required, or patterns across groups of codes. In a purely practical sense, this means that a coding system is kept manageable (subcodes are not repeated across different trees; each can be a subcategory of only one “kind of thing” and therefore has its own place). This type of structure helps the researcher to “see” what her data are about – what kinds of concepts are involved. An added benefit for a supervisor of students engaged in qualitative research is that the structure and content of the coding system efficiently conveys the clarity and depth of a student’s ongoing analysis.

As codes are being moved in the process of structuring a coding system, increasingly attention is turned from the individual sources to retrieving, reviewing, and rethinking the concepts being worked with in a project. Descriptions will have been provided for codes when they were first created, or perhaps as further data are being added to them and further clarification is needed, or they are provided now as they are being moved around. During this structuring process, further memos about the coding process are likely to be added to existing journals or memos, or new memos are created and linked to specific codes, with each holding information or thoughts

about that particular category, its nature, and what it might be associated with (to guide future queries). Consideration is given to what “job” each code is doing and how it might be used in later analyses. Codes that have only a few passages coded to them can be revisited and compared with others representing similar concepts, to see if they might be combined (if so, this warrants a note in the description and/or in the methodological journal). Others might benefit from being split – coded on to different categories instead of, or in addition to, the original categories. As with text from sources, any thought-provoking segment found in the coded data can be linked to a note in a memo. When the linked segment is retrieved, it will be shown in its original (document or image) context.

All of this activity (and interpretive thinking) is building an ever-deepening understanding of the data in the researcher’s mind. As the coding, connecting, and memoing processes are proceeding, the researcher will sometimes use query tools offered by the software to check on aspects of coding. For example, has text coded for emotions also been coded for what gave rise to those emotions? This can be checked simply by retrieving the codes for various emotions and reviewing coding stripes. Was coding applied to all the times when patients expressed satisfaction with a service? A text search will locate all the times satisf* or related words (e.g., good OR lik* OR happ*) occurred in the text and retrieve these showing the surrounding paragraph, so that coding can be checked. Even better, the search can be set to exclude passages already coded with satisfaction by using a query that combines a text search with a coding query.

Visual charting and mapping tools also continue to have a role as coding proceeds. Charts provide an overview of the coding for particular sources; coding stripes show the dominance and combinations of codes used in coding a source; coding stripes also show those codes that intersect with a code being reviewed; and simple conceptual maps created by the researcher serve as a visual aid in capturing ideas about connections in data, including literature. Visual tools based on coding are useful in an exploratory sense. For example, a coding comparison diagram shows the cases (or sources) coded at one or another or both of two concepts, prompting thoughts about the relationship between these concepts. Thus, Fig. 6 suggests the possibility of a strong relationship between social connection and engaging in physical activity in that most participants attending “Wellness Centers” for older women spoke of both, and no one spoke of activity without also speaking of social connection. Alternatively, a cluster analysis of codes, based on commonality of words used, suggests relationships between pairs of codes that might warrant further investigation, as well as, in this case, pointing to the possible dimensionality of the concept of well-being for older women, based on the grouping of codes (indicators) used to describe it by those attending Wellness Centers (Fig. 7).

A final step, before interrogation of data starts in earnest, is to review the content coded at each coding category, firstly just to check that all the content coded there “belongs” (checking consistency is a way of assessing coding reliability, without confounding the situation by having someone with a different perspective try to duplicate the coding process). More usefully, from the point of view of analysis, a review and summing up of each code clarifies both focus and boundaries for that

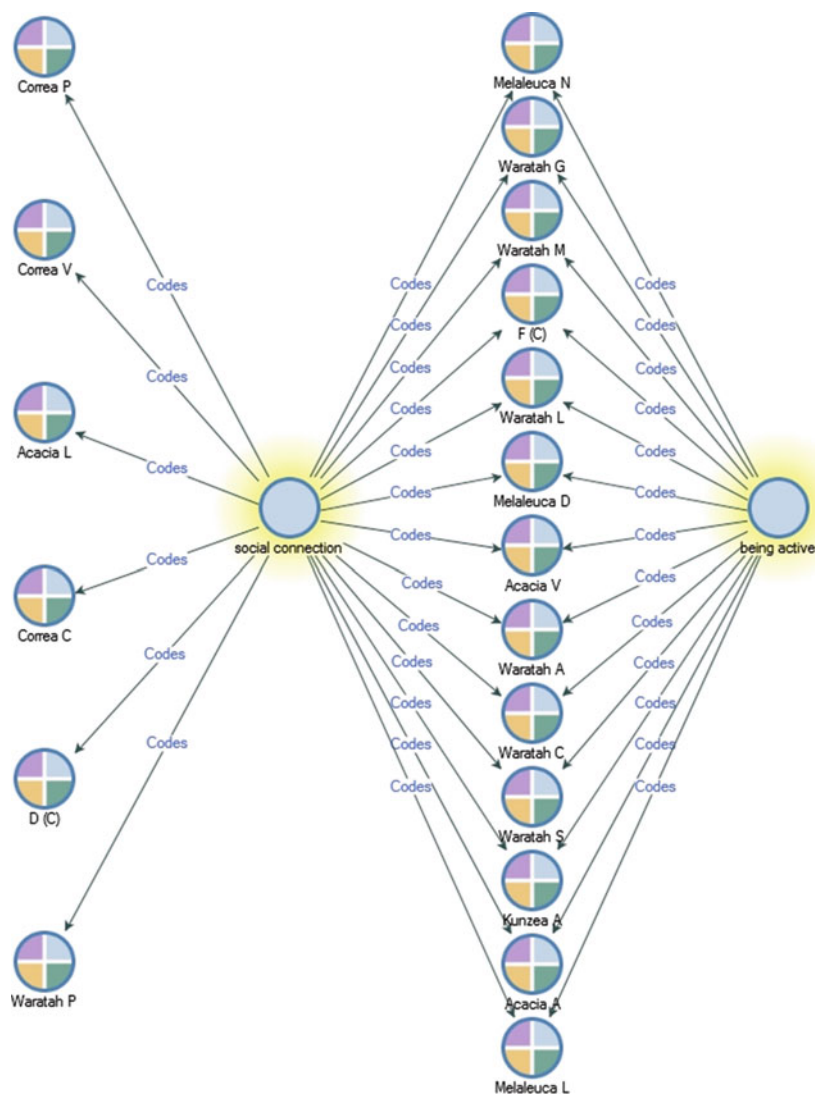


Fig. 6 Coding comparison diagram showing cases coded at social connection and being active

concept, provides the descriptive beginnings of a report of results (helping to solve writer's block), and brings to light issues for further exploration – lines of investigation that will take the analysis beyond description of “themes.” These summaries might be recorded in memos linked to the codes, with the issues for further investigation noted in the project journal. Alternatively, record the summaries directly into Word, using headings to identify each so that the navigation pane (document map) can be used to quickly locate them when further information becomes available.

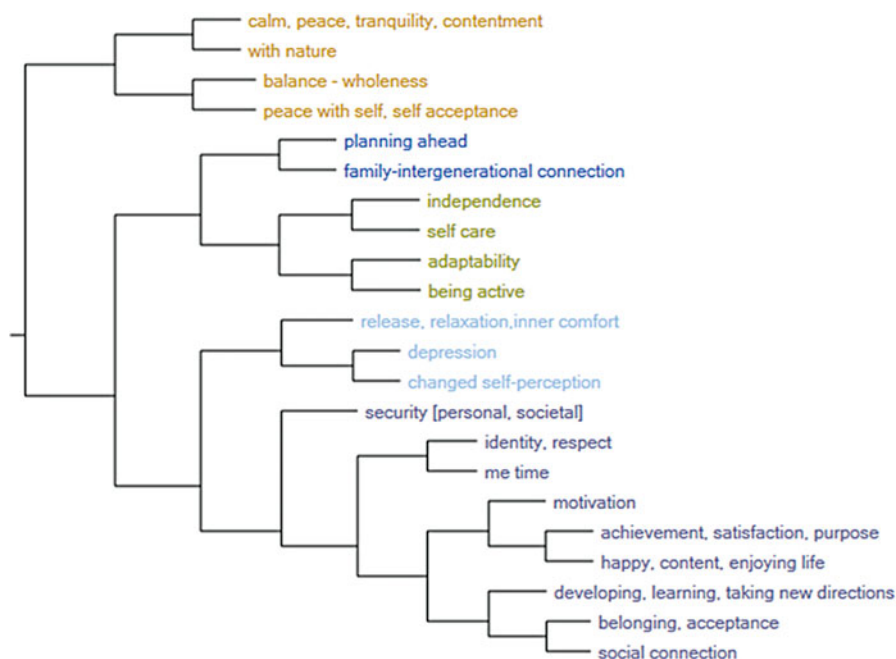


Fig. 7 Clustering of codes used to describe well-being by older women

7 Investigate and Interrogate

The qualitative researcher is developing analytic ideas throughout coding and related processes, particularly as a review of coded data is undertaken. A point is reached, however, where the focus shifts to a more deeply interpretive phase, where the researcher seeks to not just see but to understand the data and what can be learned from them, to answer the research questions, and to meet the purpose of the study. Actually, reviewing those research questions is advised at this stage because questions often shift to some degree through the course of a project. Once reviewed and realigned, the questions provide a guide to the direction of these further investigations, although some flexibility is advised as interesting leads can appear “late in the day” (although perhaps these should be set aside for later investigation, especially when a deadline is involved).

Some incidental queries using the software might have been conducted along the way, as coding and structuring of the coding system was proceeding. At this stage, however, a process of deliberate and systematic querying is more likely, as patterns and connections in the data are investigated in the search for answers. Comparative analyses are good ways to start interrogating the data. Qualitative text (or other data) is compared for different subgroups of the sample, defined by values of demographic or other quantitative variables that have been stored as attributes attached to cases.

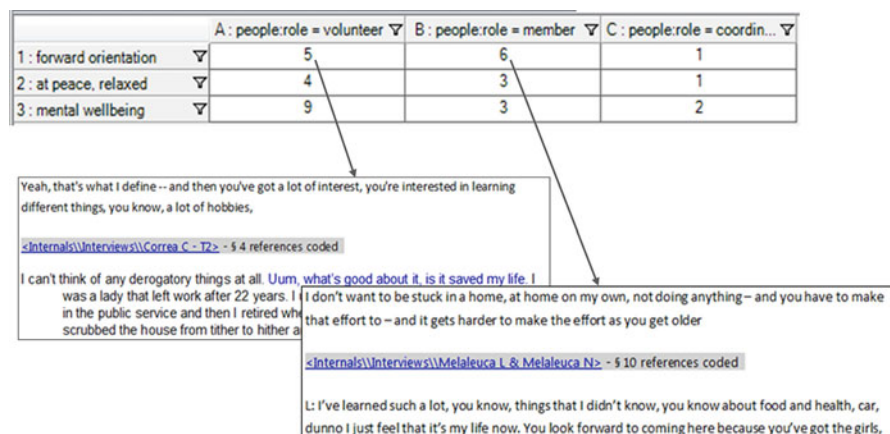


Fig. 8 Comparison of some ways in which well-being is described, for people playing different roles in Wellness Centers

In NVivo, a matrix coding query is used for this purpose (other QDAS offer equivalent tools). This provides the analyst with two kinds of data – the frequency with which different subgroups discuss the topics or experiences or issues being considered and what is actually said about each of those by each subgroup. For example, Fig. 8 compares what is said about some aspects of well-being for those who have different roles at Wellness Centers. Comparative analyses such as these are directly (descriptively) useful where comparative research questions were asked; analytically they are of value in prompting further investigation, such as why it is that this group had a different pattern of responses from that one – was it because...? Comparative analyses sometimes also reveal (sub)dimensions within concepts, when sampled groups have different ways of talking about the same concept. For example, communication patterns attributed to doctors might be compared according to whether they were described by nurses who do or who do not rate their approachability as an important issue, to reveal tacit differences in the way communication is perceived (e.g., two-way versus one-way) by these groups of nurses. These kinds of comparative queries are, therefore, useful for both exploratory analysis and for more directed analyses. Additionally, they can be extended to answer more complex three-way questions combining information from cases, sets, and codes, as described earlier.

The matrix coding query is useful also for investigating patterns of relationships between groups of codes. For example, different (reported or observed) patient in-hospital experiences might be examined in relation to emotional responses of those patients, or perhaps in relation to patterns of adjustment or recovery once discharged. For a project evaluating strategies used to build adherence to guidelines for healthy eating (or exercise or medication use), the way in which specific strategies were implemented can be reviewed in relation to whether they were considered helpful or not in terms of observable outcomes, as well as to how patients responded to each, and under what circumstances they were helpful – or indeed, some combination of these.

The way a coding system was structured is critical if it is to allow for asking a variety of questions, such as these – in the latter evaluation example, segments of texts describing responses to strategies would have been coded for the strategies being referred to, and in separate codes, whether they were observed to be useful, how the patient responded, and what the circumstances were at the time, with each of these codes being grouped in different “trees.” This might appear, at the time of coding, to be unnecessarily fracturing the data, but the consequence is that it allows for flexibility in asking questions of the data when it comes time for analysis. Had strategies been listed in just two trees, as being helpful or not, then it would be difficult to ask further questions about other responses or influences.

Particular and/or more complex combinations of specific codes (or codes and attribute values) suggested either in earlier memos based on impressions when working with the data or through the kinds of visual and pattern analyses just described, might be assessed using regular coding queries, which will return all text satisfying the criteria set for the query. As for results of matrix queries, it is then up to the researcher to interpret patterns within the data that are revealed through the query.

Reporting from a qualitative or mixed methods study is best developed as the study proceeds, initially using the in-project document/memo system and the program’s visual tools for mapping concepts and relationships, but then using a word processor alongside the qualitative software to record descriptions, insights, quotes, and helpful visual displays. The software thus provides an “evidentiary database” (Yin 2014) to be drawn on to support claims in the report.

8 Conclusion and Future Directions

What should be evident from the description given of these various processes for working with data when using software is the intensity of the way in which the researcher interacts with her data, putting to rest any possible claim or thought that using a computer might create distance between researcher and data (Jackson *in press*). Qualitative researchers using software find it contributes to the rigor and transparency of their research processes and especially to the depth of analysis they are able to achieve. The software does not provide neat answers to the research questions; rather it is a tool that facilitates working with the data in ways that will provide the evidence needed for the researcher to make judgments and reach conclusions that are supported by data. Ultimately, of course, the responsibility for the depth and quality of the analysis and interpretation of results lies with the researcher.

In an increasingly digital world, qualitative and mixed methods researchers will also increasingly adopt digital technologies to aid their research work. And the imperative of business survival means that software developers will continue to develop new tools to assist that work. Qualitative software has moved progressively into managing an ever-expanding range of data types. There has been progressive development also in the kinds of analysis strategies that are supported, with the focus

shifting most recently to automation of coding and now to mixed methods analysis, including basic statistical operations. Programs are handling ever-increasing volumes of data, which in itself requires new strategies for analysis. These trends in development will bring new opportunities but also pose (or repose) threats to those who see such moves as eroding the “real,” “intimate” character of qualitative research. Software *will* continue to support small-scale, intensive research; at the same time, it will increasingly develop to capture new, volume-oriented markets. The future scenario will offer choice, but that choice will not necessarily be “either-or.” Predictive coding strategies incorporated into software are improving in their capacity to apply machine learning, but perhaps of more interest are the moves afoot to develop and capitalize on “citizen science” and crowdsourcing strategies for hand-coding large volumes of data (Williams and Burnap 2015; Adams 2016) that are then fed into software used to assist with the (researcher-directed) analysis of those data.

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Sequence Analysis of Life History Data

53

Bram Vanhoutte, Morten Wahrendorf, and Jennifer Prattley

Contents

1	Introduction	936
2	Why Use Sequence Analysis?	936
3	What Are Sequence Data?	939
4	Sequence Analysis Toolbox	941
4.1	Descriptive Graphical Visualizations	942
4.2	Numerically Descriptive Tools	945
4.3	How to Compare and Group Sequences? On Costs and Distances	948
5	Conclusion and Future Directions	950
	References	951

Abstract

This chapter is an entry-level introduction to sequence analysis, which is a set of techniques for exploring sequential quantitative data such as those contained in life histories. We illustrate the benefits of the approach, discuss its links with the life course perspective, and underline its importance for studying personal histories and trajectories, instead of single events. We explain what sequential data are and define the core concepts used to describe sequences. We give an overview of tools that sequence analysis offers, distinguishing between visually descriptive,

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numerically descriptive, and more analytical techniques, and illustrate concepts with examples using life history data. Graphical methods such as index plots, chronograms, and modal plots give us an intuitive overview of sequences. Numerically descriptive tools including the cumulative duration, number and duration of spells, as well as sequence complexity give a more statistical and quantitative grasp on the key differences between sequences. Comparing how similar sequences are, by calculating distances, either between sequences or to an ideal type, allows grouping sequences for more analytical research purposes. We conclude with a discussion on the possibilities in terms of hypothesis testing of this mainly explorative analytical technique.

Keywords

Sequence analysis · Sequence data · Life course · Life history data · Retrospective data · Visualization · Optimal matching analysis

1 Introduction

Our lives are like threads unwinding from a spool: the longer we have lived, the more thread lies behind us. As time progresses from birth onward, biographical life histories unfold for all of us over different aspects of our lives: where we have lived, what jobs we have had, and what partners we lived with. These personal histories contain valuable information to understand the situation of a person today. Just like a patient's medical history is essential for a doctor making a diagnosis, personal histories can be a valuable part of quantitative research. Sequential data, or ordered successions of stages and states, can be statistically investigated with a tailored set of techniques: sequence analysis. Rather than designating a specific method, sequence analysis refers to an approach that comprises a group of analytic methods. The adaptation of this technique, from its origins in bioinformatics to study DNA and RNA to social processes, began with the work of Abbott (1995) and has recently gained impetus by a range of new methodological developments in response to life course applications (Aisenbrey and Fasang 2010). This chapter provides a gentle introduction to the main concepts and ideas of sequence analysis and illustrates some applications in the field of epidemiology and sociology from a life course perspective, without going into too much technical detail.

More in-depth information, as well as a broader discussion of the key concepts of sequence analysis, can be found in Blanchard et al. (2014) and Cornwall (2014).

2 Why Use Sequence Analysis?

Most aspects of our life can be imagined in a dynamic way, as a series of transitions from one stage to another, reflecting both developmental and social changes we go through as we age. This personal trajectory through life, and its relation with the

specific historical context in which each phase or transition takes place, should be taken into account to better understand someone's current situation (Abbott 1995).

A first reason to use sequence analysis is to bring *personal history to the foreground* of the analysis. We usually implicate a person's background by using synchronous measures and assume they refer in the same way to the past and social origins of all respondents.

As an example, let's discuss the social gradient of health in later life. Health inequalities have shown to be strongly related to social class during working life (Marmot et al. 1988). Taking a fundamental cause approach (Link and Phelan 1995), many researchers use educational level or occupational class to highlight these disparities (see, e.g., Arber and Ginn 1993), although the graduation ceremony lies decades in the past and older people are no longer on the job market. Implicitly, these models assume that the knowledge acquired at school or the past relation to the means of production plays a role in understanding health. Nevertheless, the actual meaning of education in terms of job opportunities differs greatly between generations (Roberts 2009), and equally when and how someone retires has shown to matter greatly for mental and physical health aspects (Marshall and Nazroo 2016; Wetzel et al. 2016). These commonly ignored historical and biographical contexts nevertheless strongly influence health in later life: actual trajectories of employment over the life course offer additional explanations of how well-being differs between people, over and above both parental and own occupational class, as well as current income (Wahrendorf 2015). In conjunction with work histories, family histories have equally shown to be strongly predictive of later life disability and mortality (Benson et al. 2017). More important than the empirical fact that these trajectories matter statistically is that they offer a more complete, and compelling, narrative about how specific patterns in a person's life lead to a certain outcome than a combination of isolated pieces of information, such as educational level, occupational class, and material circumstances, will ever do.

Second, sequence analysis is about *focusing on holistic trajectories instead of single events* (Aisenbrey and Fasang 2010). Investigating single events, such as transitions from one state to another, can help to uncover the processes that lead to the event occurring but by definition can only focus on an isolated event. As such, it importantly leaves those who never experience the event out of the picture and narrows the focus by implicitly seeing event occurrence as the end of a trajectory, while many events are reversible. Take as an example buying a house, a crucial event that is closely related to family formation (Clark et al. 1994), as well as the most common form of capital accumulation. A recent investigation of housing careers of the English population aged 50 or older (Vanhoutte et al. 2017) illustrated that a large share tend to live in owned housing, always rented, or moved from owned to rented accommodation but never acquired a house of their own (see Fig. 1). Studying only the transition to first ownership would ignore about 40% of this sample. It would equally ignore the substantial group of people that made two separate transitions from renting to ownership at different points in their lives. Investigating the trajectory in its entirety on the other hand allows not only to investigate differences between different timings of this transition but equally to consider which people are not at risk of experiencing this event.

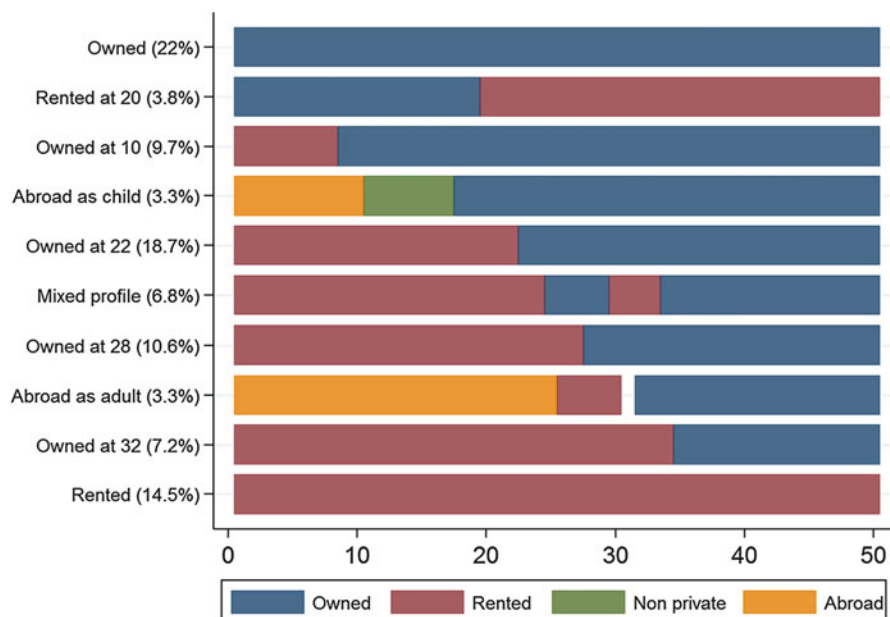


Fig. 1 Modal plot of the ten housing careers (proportion of respondents) ($N = 7505$) from (Vanhoutte et al. 2017). (The figure is created with Stata, using the `sqmodalplot` command from the `SQ` package. A detailed description of this package can be found in Brzinsky-Fay et al. (2006). For more detailed information on this type of graph, representing the modal sequence of which individual trajectories within clusters can differ, please see Sect. 3.1.3.)

Third, sequence analysis enables *translating concepts from the life course perspective* in relatively straightforward ways. Life course studies emphasize that each generation develops under unique historical circumstances that affect this development profoundly (Elder et al. 2004). Empirically, distinguishing the influence of different conceptualizations of time, such as duration, timing, and order, is crucial to use insights from the life course perspective in research (Vanhoutte and Nazroo 2016; Wahrendorf and Chandola 2016; Vanhoutte et al. 2017). Three key life course mechanisms, aligned with these three ways of looking at time, outline how exposures over the life course influence health and well-being: accumulation, critical period, and social mobility (Kuh et al. 2003; Niedzwiedz et al. 2012).

Accumulation (or cumulative duration) relates to the idea that inequalities are expressed over time and not instantaneously (Dannefer 1987; Willson et al. 2007). Small differences in an initial observation can develop into large disparities in health, wealth, and well-being, as exposures to stressors and health insults are unequally distributed over different social locations and have a strong compounded impact on health outcomes (Singh-Manoux et al. 2004; Lee et al. 2016). Accurately capturing the duration of exposure to these potentially damaging environments, such as inferior accommodation, precarious employment, or intimate relationships, in that way is an essential step to understanding the limits of human resilience to adverse

circumstances. It allows investigating to what extent a dose-response type relation exists between the stressor over the life course and the outcome under study. Therefore, the cumulative duration of time spent in a certain state can be seen as a novel and different way of looking at how (dis)advantages are embedded in the life course.

Critical period (or timing) lies behind most research on scarring early life effects (Ben-shlomo and Kuh 2002) and means that when an event happens can be crucial for the impact it has. Alongside the occurrence of the event itself, unfavorable timing can set in motion a whole cascade of knock-on effects that negatively influence the outcome. Giving birth to a child as a teenager in itself is not detrimental to health and well-being, but it can disrupt educational and occupational trajectories, having negative effects further down the road. The timing of a single transition can adequately be studied using event history analysis, but sequence analysis explicitly analyzes multiple types of transitions (between similar and different states), as well as how often they occur in specific life phases.

Social mobility (or order) is the idea that many people experience trajectories that can be characterized in terms of (social) improvement and/or deterioration. Using holistic trajectories, as sequence analysis does, allows us to establish what a typical order of succession of states is, what is not typical, and how common these specific normative or deviating trajectories are (Elzinga and Liefbroer 2007).

Aspects of duration and timing relate to descriptive aspects of sequences, and will be treated in more detail in Sects. 4.1 and 4.2, while ordering in whole sequences relates to the investigation of how entire histories unfold and are described in Sect. 4.3.

In sum, there are strong reasons to use sequence analysis when examining the social aspects of health that concern the importance of personal history for the present, the power of holistic trajectories to uncover social processes, and the possibilities to translate life course concepts.

3 What Are Sequence Data?

In contrast to other statistical techniques, the aim of sequence analyses is not to merely link different variables to each other but to enable an in-depth analysis of entire life courses, by visualizing, summarizing, and grouping sequences. The unit of analyses is the sequence itself, and it contains detailed information on individual life courses for an extended time frame.

Now what exactly is a sequence? A life history sequence represents a series of successive experienced states. Sequences are characterized by the nature of these states and the structure of the timeline along which they are positioned. The finite list of states that can occur at each time point is given by the sequence *alphabet*. Each state in the alphabet has an associated symbol that is usually reflective of its meaning (Cornwell 2015). A *spell* is a set of adjacent identical states, and a *transition* occurs when an individual moves between two different states.

Sequences depicting life course phenomena can be positioned along an age, calendar year, or some other appropriate timelines, including wave of data collection. The most suitable metric for time depends on the outcome and aims of the research project. The chosen unit and scale should reflect the rate at which the process under study is expected to develop and unfold throughout the period of interest (Singer and Willet 2003).

As such, sequence data require the descriptions of a specific state (e.g., whether the respondent rents or owns his accommodation as above) available for a chronological order (e.g., the age of the individual). While such data used to be rare, their availability has recently grown quickly, for at least three reasons: first, the number of prospective studies is rising together with longer observation periods. In some cases, this provides sequence data that can last over 20 years. However, the richness of this data does also depend on the number of measurement points within the study. For example, if data collection lasts 20 years and occurs every 5 years, then the sequence is likely to be restricted to four measurement points only (even without attrition). Second, the use of administrative data has increased substantially. Examples are administrative records of employment histories from national pension insurances, with details on different jobs (including start and end). Restrictions of use of administrative data, though, exist in terms of data protection regulations and the fact that data is not collected for research purposes. Administrative data, nonetheless, are of high accuracy and – if accessible – an efficient and cost-effective way to gain data, as it does not require personal interviews. A third, important reason for the increasing availability of sequence data is the methodological developments in the field. An increasing number of studies collect information on individual life courses retrospectively, using an event history calendar. Hereby, data collection does not occur in a conventional face-to-face interview where people just give answers to various questions. Rather, the collection of data occurs on the basis of a graphical representation of a life course (or a “calendar”) that is filled out during the interview (Belli 1998). This calendar usually contains different life domains (e.g., work, partnership, accommodation, and children histories). Studies show that calendar interviews improve the accuracy of retrospective information, as they help to memorize previous life events (Belli et al. 2007; Drasch and Matthes 2013). Furthermore, the life grid approach allows for comparable information (referring to different time points) to be collected, without producing missing data due to panel attrition in a prospective survey. Calendar interviews have now been used in several studies, including the English Longitudinal Study of Ageing (ELSA); the Survey of Health, Ageing and Retirement in Europe (SHARE) (Schröder 2011); the Australian Life Histories and Health (LHH) study (Kendig et al. 2014); and the US Health and Retirement Study (HRS). Access to harmonized key sequence data in ELSA, SHARE, and HRS is forthcoming through the website www.g2aging.org. (See also ► Chaps. 68, “Semistructured Life History Calendar Method,” and ► 69, “Calendar and Time Diary Methods.”)

In all three cases (prospective, administrative, and retrospective data), the resulting sequence data can be presented an alphabetical string, where each letter represents a specific state at a given time. As an example, the table below presents

Table 1 Examples of employment sequences and brief description

Id	Sequence 25–45	Brief description
1	WWWWWhhhhhwwwwwwwwwwww	5 years of full-time work, followed by an episode of home or family work and part-time employment thereafter
2	WWWhhhhhwwwwwwwwwwwwww	3 years of full-time work, followed by an episode of home or family work and part-time employment thereafter
3	WWuuuuWWWWWWWWWWWWWWWW	Full-time work with an early 4-year episode of unemployment
4	WWuWWWWWWuWWuWWuWWWW	Full-time work with repeated episodes of unemployment

Note: “*W*” full-time work, “*w*” part-time work, “*u*” unemployment, “*h*” home or family work

four possible employment sequences. We distinguish between four occupational situations (“*W*” = full-time work; “*w*” = part-time work; “*u*” = unemployment; “*h*” = home or family work) and focus on histories from age 25 to 45, thus covering 21 years of the working career.

The sequences in Table 1 differ with respect to the set of constituent states, the age when each state occurs, and the order in which they are experienced. The duration of individual spells, and the total time spent in a state, can also vary across sequences (Studer and Ritschard 2016). The first sequence represents a person that worked full-time at the beginning, then had a 4-year episode of home or family work (possibly maternity or paternity leave), and thereafter started to work part-time until age 45. Similarly, the second person also started with full-time work and had a 4-year episode of home or family work before reentering the labor market as part-time worker. However, compared with the first person, the episode of home or family work occurred 2 years earlier. The first two sequences consist of the same set of states but differ in the timing of home or family work and the duration of full-time and part-time work spells. The third and fourth sequences in Table 1 contain a different set of states than the first two and differ from each other with respect to the timing and duration of the constituent unemployment and work spells. While both individuals spend a total of 4 years in unemployment, person three experiences these consecutively, following 2 years of full-time work and with further uninterrupted full-time employment thereafter. The fourth person experiences repeated episodes of unemployment of a 1-year duration.

4 Sequence Analysis Toolbox

The sequence analysis toolkit includes both visual and numeric methods for describing life history data. Essential definitions and key concepts that underpin these methods are defined in this section, and an overview of index plots and chronograms is also given. These are two graphical approaches that give insight into the

composition and structure of life history data. Brzinsky-Fay (2014) has comprehensive advice on presenting and interpreting the type of graphs introduced here.

The examples used below are based on complete data, in that there are no missing values in the sequences. Every individual in the sample has a known state at each time point. However, in more complex cases, sequences may be incomplete with missing values either at the left or right end of the timeline and/or at any point within the period of interest. For the purposes of this exposition, sequences have the same beginning time, the same end point, and no gaps in between. Cornwell (2015) and Halpin (2016) discuss methods for addressing missing values in sequence data.

4.1 Descriptive Graphical Visualizations

4.1.1 Index Plot

An index plot uses line segments to graph each individual sequence in the sample. Plots are read from left to right and show how individuals move between states over time. A change in color denotes a change in state or transition. Fig. 2 plots family history using data collected for 2547 women, from the life history module of the English Longitudinal Study of Ageing (ELSA). For each year of age between 15 and 60 inclusive, a woman's family status is recorded as either single with no children, married with no children, single with children, or married with children. In this figure, a single childless woman who marries, has children, and then becomes single again is represented by a horizontal line that changes from green to red, to blue, and finally to yellow.

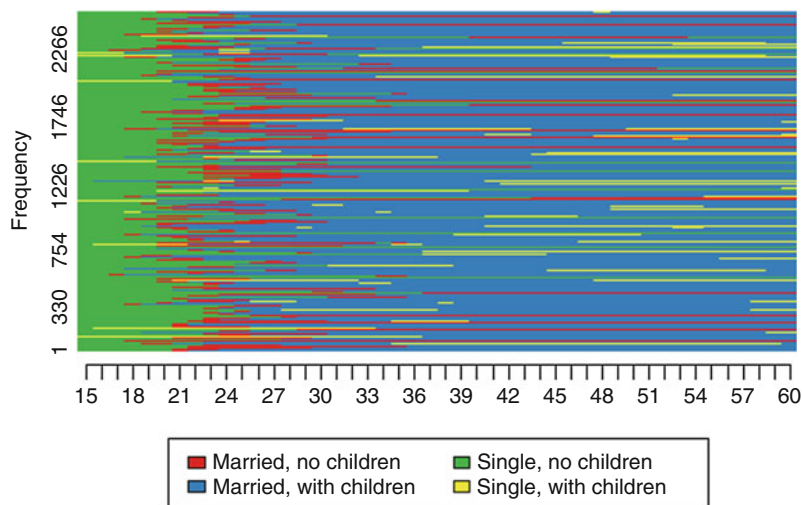


Fig. 2 Index plot of women's family history ($N = 2547$). (The index plots in this chapter are created using the Traminer package in Gabadinho et al. (2011), offering a comprehensive tool to conduct sequence analyses. See also <http://traminer.unige.ch/> for more information.)

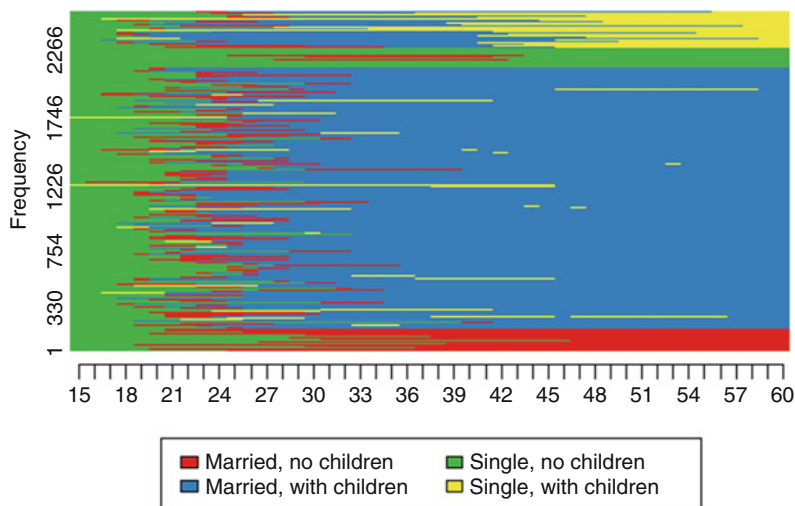


Fig. 3 Index plot of women's family history, sorted by state at age 60 (N = 2547)

The readability of an index plot, and its utility for detecting patterns, can be improved by sorting the plotted sequences according to either the first or last recorded state or value of some other attributes of interest. Fig. 3 plots the same sequences as in Fig. 2 but organized according to the marital and family status of each woman at age 60. This gives four distinct groups. Reading from bottom to top of the graph, women who are married with no children at age 60 are plotted first. Typically, these individuals married in their 20s and remained childless throughout their life course. The next group of women forms the majority of the sample. They differ from the previous group in that they married but had children. The third set of sequences is comprised primarily of women who remained single for the duration of the studied time. A minority of this group married in their late 20s but were single again by their mid-40s. The final set of sequences, at the top of the plot, represent women who were also single at 60 but had children. Most of these individuals were married during their midlife and became single by age 55. The duration of their marriage spell varies as shown by the blue portion of these trajectories.

Figure 4 shows the women's family history sequences grouped according to level of education. The top left figure is an index plot for 480 women with high levels of qualification; the bottom left plots 585 sequences for women with a mid-level of education, and top right is an index plot for 1456 women educated to a low level. Twenty-six women are removed from the sample due to missing education data. Within each cluster, sequences are sorted by work status at age 15.

Grouping index plots in the way described allows cross-sectional comparisons of the proportion of women in each state at each time point. Longitudinal sequence features, including the duration and timing of spells, can also be compared. Fig. 4 shows that, compared to the low and medium education groups, the high attainment sample contains a higher proportion of women who are single and childless at

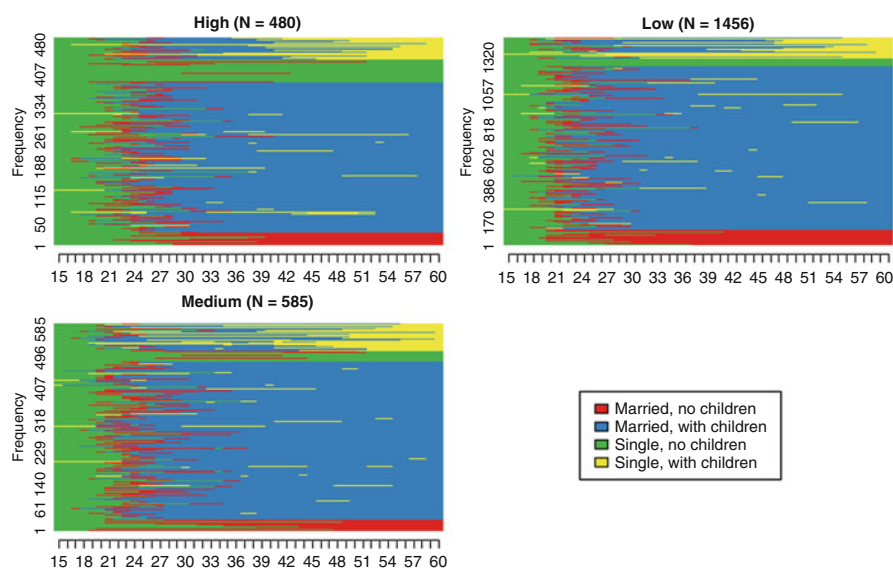


Fig. 4 Index plot of women's family history, by level of education

age 60, and there is some variation in the timing and duration of marriage spells among women who are single with children at 60. Those with a high level of education tend to have shorter marriage spells, and spend a correspondingly longer time single, than less well-qualified women. The proportion of 60-year-old women that are married without children is similar irrespective of education level, but the age of marriage tends to be younger among women with low education than those more highly qualified.

4.1.2 State Distribution Plot/Chronogram

A state distribution plot shows the proportion of observations in each state for every time point. This graph, alternatively known as a chronogram or state proportion plot, contains no information on individual sequences; rather, it is useful for describing changes in the composition of a sample or group over time. Time is positioned on the horizontal axis, the proportion or percentage of observations in each state is given by the vertical axis, and the graph is read vertically at each time point.

Figure 5 is a chronogram of women's family sequences from ELSA, as graphed in the index plots in Figs. 2 and 3 above. At 15 years old, 99% of women are single with no children and 1% single but with children. By age 23, there is more diversity in the sample. The proportion of single women with no children has fallen to one third; 29% are married, but childless, and 35% are married with children. The proportion of single women with children increases over time, to a maximum of 11% at age 60. At age 60, 77% of women are married with children, 7% are married without children, and 5% are single and childless. As with sequence index plots, separate

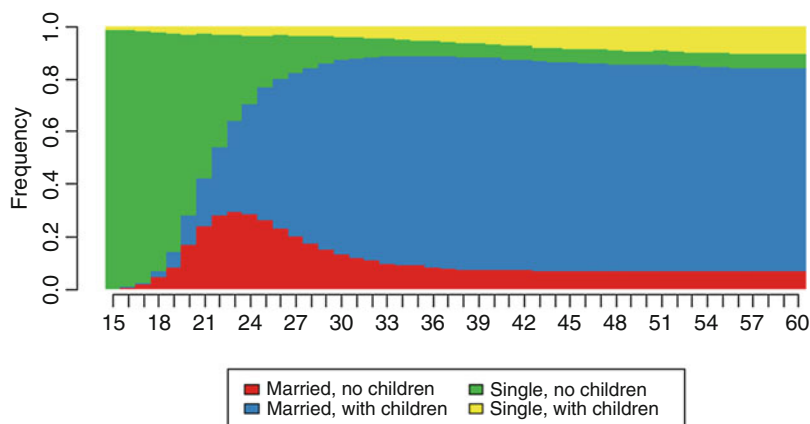


Fig. 5 Density plot of women's family history (N = 2547)

chronograms can be drawn for subsets of a sample, allowing state distributions to be compared across groups differentiated by an attribute or characteristic of interest.

4.1.3 Modal Plots

A modal plot shows a representative sequence for a cluster or group (Aassve et al. 2007). The most common state at each time point is plotted, although the resulting sequence may be artificial and not present in the studied dataset. Fig. 1 above is an example of a modal plot, which shows representative sequences for each of ten clusters, formed from plotting the most common housing status at each year of age.

4.2 Numerically Descriptive Tools

While some life courses are quite simple and stable, others are more complex and varied. As illustrated in the previous paragraph, visual inspection can give us a feel of how sequences differ from each other. Quantifying their properties allows an even more precise and in-depth comparison, as well as enabling the use of descriptive summary statistics of sequences in further analysis. Examining these properties of sequences by different genders, social groups, or cohorts can help to answer a number of research questions, such as those concerned with the increasing complexity within and between life courses, named, respectively, the differentiation and destandardization of the life course (Aisenbrey and Fasang 2010).

As said earlier, sequences can differ from each other in five aspects: experienced states, state distribution (or total time in each state), timing (or time point at which a state appears), duration (or length of a spell), and sequencing (order of states) (Studer and Ritschard 2016). In terms of descriptive metrics of sequences, three main properties related to these aspects emerge: cumulative duration; timing, number,

and duration of spells; and complexity (Utilities to calculate these measures are available in the SADI package in Stata (Halpin 2017)).

4.2.1 Cumulative Duration

The most evident descriptive statistic of a sequence is the cumulative duration spent in a certain state. This metric reflects both the experienced states and the state distribution of a sequence. Comparison of the average total time spent in a state by cohort is a straightforward way to understand demographic changes (Billari 2001). Cumulative duration, as a total sum or count of the amount of time spent in a certain state, can equally function as a measure of exposure to circumstances associated with this specific state, in a logic of cumulative (dis)advantage (Wahrendorf and Chandola 2016; Vanhoutte et al. 2017). Cumulative duration might help to understand what type of relationship exists between exposure and outcome. Is there a dose-response relationship between number of years out of work and health in later life, or is it simply about passing a certain threshold? A crucial benefit is that using sequence data to grasp the length of exposure gives a more reliable answer than the straightforward question how long a person was unemployed. While duration is straightforward to calculate, it does have a number of drawbacks which are intuitively understood when examining our example sequences.

Consider Table 2, which contains three different, straightforward employment sequences of ten observed time points (years), with two possible states U and W, designating unemployment and employment, respectively.

Person A has a cumulative duration of 10 years in an employed state and a duration of zero in an unemployed state. Both persons B and C spent 5 years in each state, although their sequences are very different from each other. Note that person A has a different set of experienced states (only W) than persons B and C (U and W). A second point is that all three people might have been working in several workplaces during their years of employment. As such, duration as a metric does not say anything about the number of transitions, either within or between states. The maximum cumulative duration is the total time observed, while the minimum cumulative duration is the unit in which time is measured.

4.2.2 Timing, Number, and Duration of Spells

A second set of sequence descriptors relates to the timing, number, and duration of spells. A spell is defined as a period of continuous time spent in one particular state. Spells can be of short or long duration, and there can be multiple spells of the same state within a sequence, with each starting at a different point in time. The minimum

Table 2 Examples of 10-year employment sequences

Person	Sequence 25–35
A	WWWWWWWWWW
B	UUUUUWWWWW
C	UWUWUWUWUW

Note: “W” full-time work, “U” unemployment

number of spells is one, and the maximum possible is the total number of observations that each person has. Comparing the number, duration, and starting time of spells across sequences allows us to compare the timing and continuity of peoples experiences, and distinguish between those who have experienced the same states, and the same amount of cumulative time in each state, but who differ in terms of how stable their life histories have been.

Comparing spell attributes is meaningful when looking at life histories of a career type, like occupational or housing. Consider the difference between person D with sequence U U U U W W W W W W and person E with a sequence UWUWUWWWW. In both cases, they have spent a total of 4 years in unemployment and 6 years in work. However the spells within each sequence differ in terms of number and duration; person D has two spells, one of unemployment and one of work. They are 4 and 6 years long, respectively. Person E has a more disrupted work history, with eight spells in their sequence; seven are 1-year long, and one is 3 years. The time at which each person settled into longer-term employment differs, with person D entering more stable work in their fifth year, but person E not doing so until the eighth year. This example illustrates the importance of concurrently examining both the number and duration of spells, as well as timing, to maximally distinguish between sequences. While it is important to study transitions between different states, for example, the transition from unemployment to employment, it is equally important to look at how time within one state is experienced over the life course, and these differences can only be investigated when sequences are examined in terms of the features described here.

4.2.3 Complexity

A third set of descriptive statistics summarizes how complex sequences are internally. One often used measure is Shannon's entropy index, which originated in information theory and reflects how predictable a sequence is (Billari 2001; Widmer and Ritschard 2009; Elzinga 2010). Shannon's entropy is calculated based on the cumulative duration of each observed state in a sequence. The index is 1 when all possible states have the same duration and 0 when only one state is observed. As stated before, cumulative duration in itself does not reflect number of spells, so some authors use an adapted index multiplied by the number of spells over the maximum possible number of spells (Vanhouette et al. 2017).

A second measure of sequence complexity is turbulence, named after the term from hydrodynamics that designates an unstable speed and direction of flow (Elzinga 2003; Elzinga and Liefbroer 2007). Turbulence is based on how many different subsequences we can detect in each sequence and reflects differences in order (Elzinga 2010). Subsequences are the unique building blocks of sequences, and the more different building blocks can be distinguished in a sequence, the more complex it is. For example, while the sequence "aaa" counts three subsequences (a, aa, and aaa), sequence "aba" counts five subsequences (a, b, ab, ba, and aba) and hence is more complex. The measure takes into account duration in a state, and is the logarithm of the weighted count of subsequences, which can be normalized.

The following example highlights the difference between the entropy and turbulence measures. Consider the sequence `abcabcabc` and a sequence `aaabbbccc`; these have the same total time spent in each state, and as such the Shannon's entropy index will be the same for both sequences (0.333). However, the second sequence is more stable and less complex than the first one and will hence have a lower adapted Shannon's entropy index. The adapted index, accounting for the number of spells or transitions, is higher for the first sequence, as it contains 9 transitions over 9 time points, and hence is weighted as $1 = 0.333$. The second one contains 3 transitions over 9 time points and is weighted by a third $= 0.111$. For the first sequence, turbulence is 8.35 (or 1 normalized) and for the second it is 7.04 (or 0.70 normalized).

4.3 How to Compare and Group Sequences? On Costs and Distances

The examples in this chapter illustrate how sequence analysis provides a set of different numeric measures (e.g., cumulative duration in a state) and techniques of visualization (e.g., index plot with a line for each sequence in the data) to describe entire sequences. Beyond that, sequence analysis allows us to explore if the observed sequences in the data share similar patterns and regroup sequences with similar patterns into meaningful clusters. This helps to reduce the complexity and variety of individual trajectories and to identify specific types of sequences (e.g., types of employment histories).

An important step toward this aim is to quantify how similar or different an individual sequence is relative to another sequence and to calculate a dissimilarity measure. One commonly used approach is to ask how many changes are needed to turn one sequence into another (for a more comprehensive discussion of dissimilarity measures and their approaches, see Studer and Ritschard 2016). Most simply, we could count the number of necessary substitutions to make one sequence equal to the other. In the case of the two sequences `ABCABC` and `CABCAB`, for example, this would mean that we compare sequences element by element and in this case need to substitute each element to turn the first sequence into the second. To quantify this transformation (and to obtain a dissimilarity measure), we need to define the substitution cost. Substitution costs are the value assigned to each performed substitution and are commonly defined by the researcher (for other possibilities, including “data-driven” costs, see Studer and Ritschard 2016). For example, if substitution costs are set to one in our example, then the transformation would cost six points (which is the maximum distance for a sequence of this length). In the literature, this strategy is usually referred to as “naïve distance” or “traditional Hamming distance” with consistent substitution costs set to 1 (Hamming 1950; Eerola and Helske 2016).

This strategy has one important limitation: similarities at different time points in the sequence are not recognized. Specifically, in our example (`ABCABC` and `CABCAB`), the subsequence `ABCAB` is part of both sequences, only shifted by one place. This similarity is not recognized in case of the naïve distance and the maximum distance is assigned. Optimal matching (OM), a specific form of calculating distances within

Table 3 Examples of employment sequences and dissimilarity measures

Id	Sequence 25–45	
1	WWWWWhhhhhwwwwwwwwwwwwwwww	
2	WWWhhhhhwwwwwwwwwwwwwwwwww	
Naïve distance (hamming distance)	(subst = 1)	4
Levenshtein distance (OM distance)	(subst = 1; indel = 0.5)	2

Note: “W” full-time work, “w” part-time work, “u” unemployment, “h” home or family work

sequence analysis, resolves this problem by using a different strategy to calculate the dissimilarity, using the so-called “Levenshtein distance” (Levenshtein 1966; Eerola and Helske 2016). Hereby, two additional possible operations exist to turn one sequence into another: to insert a specific state into a sequence (“insertion”) and to delete specific states from a sequence (“deletion”). Turning back to our example (ABCABC and CABCAB), that would mean that we could insert a state at the beginning of the first sequence (insertion of C) and delete the last state (deletion of C). In that case two operations of one insertion and one deletion rather than six substitutions would be necessary to make both sequences equal. These “indel” costs (insertion and deletion) are usually set to half of the substitution cost.

To summarize these two different strategies (naïve Hamming distance and Levenshtein distance), the following table returns to the two first sequences from Table 3, that is, the two sequences that were characterized by a 4-year episode of home or family work that occurred at different time points. In case of the naïve distance, the calculated distances would be 4, while 2 would be the resulting Levenshtein distance.

Each strategy has its advantages. The OM distance is possibly more appropriate in case a researcher is interested in detecting similar patterns, while the Hamming distance puts a strong emphasis on the timing of an episode that may also be of interest in some cases.

As stated above, both strategies require costs to be defined and set. Up to this point, we have assumed that substitution costs are 1 for each possible replacement. As an example, we assumed that replacing “full-time work” (W) with “part-time work” (w) would be the same (or cost as much) as replacing “full-time work” (W) with “unemployment” (u). Depending on the goals of the analyses, this may be appropriate. But for theoretical reasons, we may want to treat a substitution of full-time work with part-time work as less expensive, and hence more alike, than a substitution of full-time work with unemployment. In that case, for example, we could specify that replacing W with w would cost 0.5 (and not 1 as before). The researcher can specify costs to vary according to replacements that occur in substitution operations. Importantly, this type of variable costing requires a clear theoretical rationale; however, there is often no reason to assume different substitution costs, and a standard unique cost structure is applied with substitution costs set to 1 and indel costs to 0.5 (as in Table 2) (Abbott and Angela 2000).

The conducted comparisons allow us to quantify how similar (or dissimilar) sequences are. When applying these comparisons in the frame of a study and based

on large datasets, two scenarios or approaches of comparisons are possible. First, we can predefine an ideal-typical reference sequence and calculate the distance of each person in the data relative to this reference sequence. For example, a researcher may be interested to know how different a person's employment history is compared with a prototypical history of continued full-time work, that is, a sequence uniquely marked by W in our example. As a result, we would quantify to what extent the employment history differs from a given typology. One such example is a recent study investigating links between work-family life courses between age 16 and 42 years and health during midlife, based on the National Child Development Study (NCDS) (Lacey et al. 2015). In that case, the authors predefined 12 ideal types based upon previous knowledge (e.g., continuous full-time work without family or early family without work) and calculated the distance from each individuals' work family sequence to this set of 12 ideal types, so that they could identify the closest ideal types. This strategy, though, has the disadvantage that it merely informs the researcher about the degree to which a respondent differs from a self-chosen prototype. It does not allow the observed sequences to be grouped into empirically derived types and thus identify sequences with similar patterns and complexity in the data.

A second approach is to compare every sequence to every other sequence in the data (without defining a reference sequence) and to use this information as a basis to group similar sequences into empirically distinct clusters. In that case, for every pair of sequences, a distance is calculated. If our sample consists of 1000 people, comparisons would produce a large distance matrix that quantifies the distance between each pair of individuals in the sample (i.e., a 1000×1000 matrix). For the purpose of grouping similar sequences into types, this information is crucial as individuals who have similar sequences will have low distances to each other, and dissimilar sequences will have high dissimilarity measures to each other. However, the resulting information is vast and in itself impossible to digest. Therefore, the standard practice is to complement the calculation of the dissimilarities with a cluster analysis that uses the matrix as basis and moves from distance matrices to typologies of sequences. The goal of the cluster analysis is to organize the sequences into groups in a way that the similarity is maximized for the sequences within a group and minimized between groups (for an overview of different clustering techniques as applied to distance matrices, see Studer 2013).

5 Conclusion and Future Directions

This chapter aims to be a gentle introduction to sequence analysis, focusing on its application using life history data to uncover the social determinants of health. We show how there are both theoretical and empirical parallels between the life course approach and sequence analysis, introducing methods for providing empirical evidence of the influence long-term processes can have on current health and well-being. As sequence analysis is a technique under continuous development, many currently topical issues did not receive attention, so as to avoid overburdening the reader. The most debated issues focus around the calculation on costs and

distances between sequences (for a recent overview of possible approaches, see Studer and Ritschard 2016), how to investigate multiple sequences (e.g., from different life domains) at the same time (see, e.g., Gauthier et al. 2010), as well as how to use sequence analysis as a predictive and explanatory tool instead of a descriptive set of techniques. While the first two issues quickly become technical and complicated, and fall outside the scope of this chapter, the third is worthwhile considering. The most commonly used sequence analysis techniques up until now, such as optimal matching, have exploited the algorithmic, pattern-seeking nature inherent in grouping sequences according to their relative distance. The resulting outcome of this process, a categorical classification of sequences that differ minimally within groups and maximally between groups, can then be used as an independent (or dependent) variable within other methods. For example, we could relate resulting clusters of employment histories in a regression to predict health in later life. While this is a justifiable approach, it remains difficult to ascertain causality in strict statistical terms between exposure and outcome, as well as to tackle shared explanatory power between these sequence categorizations and common predictors such as gender, social position, and cohort. A different approach to this issue that is currently gaining ground is the use of numerical descriptors of sequences, such as the complexity measures we described, to explain differences between social groups in a regression. These sequence metrics in a sense present a middle road between the broad all-encompassing categorical classifications, and the minute detail of the actual sequence, and can be tailored to fit specific conceptual frameworks (see, e.g., Brzinsky-Fay 2007). As such, the way forward lies in alternating the explorative and hypothesis testing possibilities of sequence analysis in combination, to achieve more insight into how our personal histories structure our present.

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Data Analysis in Quantitative Research

54

Yong Moon Jung

Contents

1	Introduction	956
2	Nature of Data for Quantitative Data Analysis	956
2.1	Significance of Understating of Levels of Measurement	956
2.2	Four Levels of Measurement	957
3	Types of Analysis Models	958
3.1	Types of Research Questions	960
3.2	Different Types of Variate Analysis	961
3.3	Types of Analysis by Purpose	962
4	Conducting Data Analysis	965
4.1	Choice of a Suitable Analysis Model	965
4.2	Practice of Data Analysis in Quantitative Research	965
5	Conclusion and Future Directions	968
	References	968

Abstract

Quantitative data analysis serves as part of an essential process of evidence-making in health and social sciences. It is adopted for any types of research question and design whether it is descriptive, explanatory, or causal. However, compared with qualitative counterpart, quantitative data analysis has less flexibility. Conducting quantitative data analysis requires a prerequisite understanding of the statistical knowledge and skills. It also requires rigor in the choice of appropriate analysis model and the interpretation of the analysis outcomes. Basically, the choice of appropriate analysis techniques is determined by the type of research question and the nature of the data. In addition, different analysis techniques require different assumptions of data. This chapter provides

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955

introductory guides for readers to assist them with their informed decision-making in choosing the correct analysis models. To this end, it begins with discussion of the levels of measure: nominal, ordinal, and scale. Some commonly used analysis techniques in univariate, bivariate, and multivariate data analysis are presented for practical examples. Example analysis outcomes are produced by the use of SPSS (Statistical Package for Social Sciences).

Keywords

Quantitative data analysis · Levels of measurement · Choice of analysis model · SPSS

1 Introduction

Quantitative data analysis is an essential process that supports decision-making and evidence-based research in health and social sciences. Compared with qualitative counterpart, quantitative data analysis has less flexibility (see ► [Chaps. 48, “Thematic Analysis,”](#) ► [49, “Narrative Analysis,”](#) ► [28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis,”](#) and ► [50, “Critical Discourse/Discourse Analysis”](#)). Conducting quantitative data analysis requires a prerequisite understanding of the statistical knowledge and skills. It also requires rigor in the choice of appropriate analysis model and in the interpretation of the analysis outcomes. In addition, different analysis techniques require different assumptions of data. When these conditions are not fully satisfied, the analysis is regarded as inappropriate and misleading.

This chapter provides introductory guides for readers to assist them with their informed decision-making in choosing the correct analysis models. The chapter begins with discussion of the levels of measure: nominal, ordinal, and scale. Some commonly used analysis techniques in univariate, bivariate, and multivariate data analysis are presented for practical examples. Example analysis outcomes are produced by the use of SPSS (Statistical Package for Social Sciences).

2 Nature of Data for Quantitative Data Analysis

2.1 Significance of Understating of Levels of Measurement

For proper quantitative analysis, information needs to be expressed in numerical formats. In order for the numbers to be the basic components of the dataset in quantitative analysis, every attributes of the variables need to be converted into numbers. This process is call coding, where numbers are assigned to each attribute of a variable. For instance, the attribute of male in *sex* variable is given the value of 1, and the attribute of female is given the value of 2. In this case, the numbers represent the attributes expressed in lengthier text terms for the purpose of quantitative analysis.

While the coding process is applied to replace any non-numerical information such as letters and symbols, the numbers do not represent attributes in the same way. This means that the nature and value of the same number can be different. For instance, the value of number 1 in the above sex variable does not have any numerical meaning but is just a shorter placeholder for male (Trochim and Donnelly 2007). However, the value of number 1 in *income* variable represents the actual value of the number. In these two cases, different meanings are attached to the same value of number 1. Put another way, the number represents different levels depending on the nature of the variable.

Level of measurement has critical implications for data analysis. Firstly, an understanding of level of measurement helps with evaluating the measurement. Each variable must be measured in such way that its attributes are clearly represented in the measurement, and the maximum amount of information is collected. Measurement evaluation can judge if the most appropriate level of measurement was selected for the collection of the best information of a variable. This will be further explained in the following section. Secondly, understanding of the level of measurement ensures the correct interpretation of the analysis outcomes. A clear understanding of what the value of the number exactly represents and what the distance among the values means guides proper interpretation. Lastly but most importantly, the level of measurement of a variable determines the choice of the analysis model. For example, *mean* value is not produced for sex variable, and subsequently an analysis model for mean comparison for sex variable simply does not make sense. The choice of inappropriate analysis model has a possibility of misdealing the discussions and conclusions.

2.2 Four Levels of Measurement

The level of measurement defines the nature and the relationship of the values assigned to the attributes of a variable (Trochim and Donnelly 2007). That is to say that the relationship between the values of 1 and 2 in sex variable is different from that in income variable. Unlike the latter case, 2 is neither greater than 1 nor double the magnitude or quantity of 1. A variety of measurements is in use in quantitative research. Most of the texts for quantitative research present four levels of measurement (Brockopp and Hastings-Tolsma 2003; Trochim and Donnelly 2007; Babbie 2016).

The first or lowest level of measurement is *nominal*. The nominal measurement is characterized by variables that are discrete and noncontinuous (Brockopp and Hastings-Tolsma 2003). The values are assigned arbitrarily, and thus it is not assumed that higher values mean more of something. The nominal level is appropriate for categorical variables such as sex (male, female), marital status (married, unmarried), and religion (Christianity, non-Christianity).

The second level of measurement is *ordinal*, where the attributes are rank-ordered along the continuum of the characteristics. The ordinal measurement is more than classifying information, and higher values signify more of things in this

measurement. However, distances between values do not represent the numerical differences. Educational attainment (high school or less, undergraduate, postgraduate), level of socioeconomic status (high, medium, low), and degree of agreement (agree, neutral, disagree) can be measured by the ordinal measurement.

The third level of measurement is *interval*. While the values do not have numerical meanings in the previous two measurements, the distances between the values are interpretable in this measurement. In this measurement, computing average makes sense. However, the interval measurement does not have an absolute zero, and ratios do not make sense in this measurement. Temperature is a typical example of the interval measurement, where 0° does not mean there is no temperature and 40° is not twice as hot as 20° .

The last or highest measurement is *ratio*. This measurement is characterized by variables that are assessed incrementally with equal distances and has a meaningful absolute zero. Height, weight, number of clients, and annual income can be measured by the ratio measurement and meaningful ratios or fraction can be calculated in this measurement. Although interval and ratio measurement are distinctive in their concepts, it is noted that they are not strictly distinguished in the data analysis in social and behavioral sciences. For instance, SPSS combines these two measurements into one measurement.

As was indicated, four levels of measurement form a hierarchy by the amount of information. Also the nature of the values in each measurement defines appropriate statistics that can be produced (McHugh 2007). Higher levels of measurement have capacity to produce more statistics. Table 1 summarizes the key features of the levels of measurement and the producible statistics.

It should be noted here that variables that can be measured by the interval and ratio measurements can also be measured by lower measurements. For instance, *income* variable can be measured by nominal (yes, no), ordinal (low, medium, high), and ratio (actual amount of income). If income is measured by the ratio measurement, it can be later reduced to ordinal or nominal measurements. However, variables measured by the lower measurements cannot be converted into higher ones (Babbie 2016). The ability to manipulate higher measurements means that a wider variety of statistics can be used to test and describe variables at that level (McHugh 2007). Therefore, it is suggested that a variable should be measured at the highest level possible (Brockopp and Hastings-Tolsma 2003; Babbie 2016). If lower measurements are used when higher measurements are applicable, it causes loss of information and decreases the variety and the power of statistics.

3 Types of Analysis Models

There is a range of analysis models available, and each model has different requirements to be satisfied. Choosing an appropriate analysis model requires a decision-making process (Pallant 2016). There are a number of factors to be considered. Basically, the choice of analysis model in quantitative data analysis is determined by

Table 1 Levels of measurement and appropriate descriptive statistics

Nominal		Ordinal		Interval		Ratio	
Features	Statistics	Features	Statistics	Features	Statistics	Features	Statistics
Discrete categories	Mode	Discrete categories	Mode	Discrete categories	Mode	Discrete categories	Mode
	Percentage		Percentage		Percentage		Percentage
		Ordered categories	Median	Ordered categories	Median	Ordered categories	Median
			Range		Range		Range
				Equal distances between the categories	Mean	Equal distances between the categories	Mean
					Standard deviation		Standard deviation
						Meaningful absolute zero	Ratio

(1) the nature of the variable or the level of measurement of the variable to be analyzed, (2) the types of research question, and (3) the types of analysis.

The importance of understanding of different levels of measurements was already discussed in the previous section. Lower levels of measurements can produce only limited statistics, and this defines analysis models that can be employed. For example, when income variable is measured in a nominal way (yes, no), only limited option is available in choosing an analysis model. However, when it is measured in a ratio way, a full range of statistics is available, and researchers are given broadened options.

This section will outline the other two considerations: types of research question and types of analysis. This will be followed by the analysis models that suit different types of research question and analysis. It is noted that each analysis model assumes certain characteristics of the data, which is also known as assumptions. Violation of these assumptions can mislead the conclusion (Wells and Hin 2007). It will assist researchers with informed decision-making in choosing appropriate analysis model.

3.1 Types of Research Questions

Research question is a question that the study intends to address and defines the purpose of the study (Creswell 2014). Research question also defines the research method and the analysis plan. There can be a range of classification of research question, but most research questions can be divided into three different categories: exploratory, relational, and causal.

Exploratory research questions seek answers to what is it or how it does. They seek to “describe or classify specific dimensions or characteristics of individuals, groups, situations, or events by summarizing the commonalities found in discrete observations” (Fawcett 1999, p. 15) by exploring the characteristics of phenomenon, the prevalence of phenomenon, and the process by which the phenomenon is experienced. The percentage or the proportion of people on various opinions and the average of any variable are primarily exploratory information in nature.

While exploratory questions typically deal with a single variable, relational research questions are interested in the connection between two or more variables. Relational research raises the following types of questions: is one variable related to the other variable? or to what extent do two (or more) variables tend to occur together (Fawcett 1999)? In other words, they seek to explore the existence of the relationship between variables (yes, no), the direction of the relationship (positive, negative), and the strength of the relationship (weak, medium, strong) (Polit and Beck 2004) (Table 2).

Causal research questions are part of the relational ones but further explore the nature of the relationship to predict the causative relationship between variables. They assume that natural or social phenomena have antecedent factors or causes (Polit and Beck 2004). Therefore, causal questions are raised after the non-causal relationships between variables are formulated. In quantitative data analysis, causal research sets dependent and independent variables

Table 2 Type of research questions

Type	Features	Example question
Exploratory (descriptive)	Categorization	What is the percentage of people who are obese?
	Identification of commonalities	
	Analyzing single variable	
Relational	Connection between two or more variables	Is gender related to obesity?
	Analyzing multiple variables	
Causal (explanatory)	Prediction of causative relationships	Does exercise make a difference in the occurrence of obesity?
	Dependent and independent variables	

to identify the causative relationships. Causal questions are also named as explanatory questions.

3.2 Different Types of Variate Analysis

The term of variate is widely used in statistical texts, but it is difficult to locate statistical literature that provides a clearly workable definition of the term. Not surprisingly “the term is not used consistently in the literature” (Hair et al. 2006, p. 4). More often than not, the term of variate is used interchangeably with the variable. For instance, some literature defines multivariate analysis as simply involving multiple number of variables in the analysis. However, the variate is strictly a different concept from the variable.

The variate is broadly an object of statistical analysis as is expressed in numbers. In this regard, it refers to the values or data. However, the use of the variate with nominal or categorical measurements is not appropriate. This is because it assumes the variance, a statistic that describes the variability in the data for a variable and is “the sum of the squared deviations from the mean divided by the number of values” (Trochim and Donnelly 2007, p. 267). Strictly, the variate is “a linear combination of variables” (Hair et al. 2006, p. 8) and, thus, requires at least two continuous variables. While keeping the conceptual difference between variable and variate, this section outlines statistical analyses in line with the convention of statistical literature that does not strictly distinguish them from each other.

When a single variable is involved in analysis, it is called univariate data analysis (when the variable is nominal, the appropriate name of the analysis is univariable analysis). Univariate analysis examines one variable at a time without associating other variables. Frequency analysis or percent distribution that describes the number of occurrences of the values is a typical form of univariate data analysis. Univariate analysis is also referred to as descriptive analysis that deals with central tendency and dispersion of variables. z-test is also can be categorized as univariate analysis. Descriptive analysis will be further explained in the next section.

Table 3 Type of analysis by the number of variables

Type	Features	Example analysis models
Univariate analysis	Examination of single variable	Descriptive analysis z-test/one sample t-test
Bivariate analysis	Examination of relationship between two variables	Cross-tabulation Bivariate correlation T-test/ANOVA Simple regression
Multivariate analysis	Examination of more than two variables	Multiple regression MANOVA Factor analysis Discriminant analysis

When more than one variables are simultaneously included in analysis, it is called multivariate analysis (again multivariable analysis is an appropriate naming when multiple variables are included in the analysis regardless of the level of measurement of the variables (Katz 2006)). However, statistical literature distinguishes the analysis that involves exactly two variables from multivariate data analysis and calls it bivariate analysis. Bivariate analysis usually aims to examine the empirical relationship between two variables. Cross-tabulation and correlation analysis are the examples of bivariate analysis (cross-tabulation can be appropriately called bivariable analysis as the variables tested are nominal). Analyses with a purpose of subgroup comparison such as t-test, analysis of variance (ANOVA), and simple regression can also fall under this category (Babbie 2016) (Table 3).

Multivariate data analysis simultaneously involves multiple measurements and usually more than two variables just to distinguish it from bivariate analysis. The techniques of multivariate analysis are mostly the extension of univariate and bivariate analyses (Hair et al. 2006). For example, simple regression is extended to multivariate analyses by including multiple independent variables. In a similar way, ANOVA can be extended to multivariate analysis of variance (MANOVA). However, the design of some multivariate analysis such as factor analysis is not based on univariate or bivariate analysis, and they are designed based on completely different principles and assumptions.

3.3 Types of Analysis by Purpose

Quantitative data analysis can also be categorized into descriptive and inferential statistics by the purpose of analysis. Descriptive analysis simply describes the variables in the sample. Descriptive analysis reduces the large amount of data into a simpler summary. The outcomes of descriptive analysis vary depending on the level of measurement of the variable. If the variable is nominal, a frequency table or a percentage distribution is a typical outcome. If the variable is a continuous

Table 4 Examples of descriptive statistics (single variable (left) and two variables (right))

Statistics			Descriptives				
Overall satisfaction with life			Gender		Statistic	Std. Error	
N	Valid	151	Overall satisfaction with life	Male	Mean	3.81	0.101
	Missing	2			95% confidence interval for mean	Lower bound	3.61
						Upper bound	4.02
					5% trimmed mean		3.83
					Median		4.00
					Variance		0.603
					Std. deviation		0.776
					Minimum		2
					Maximum		5
					Range		3
					Interquartile range		1
					Skewness		-0.117
					Kurtosis		-0.457
				Female	Mean	3.74	0.071
					95% confidence interval for mean	Lower bound	3.60
						Upper bound	3.88
					5% trimmed mean		3.77
					Median		4.00
					Variance		0.459
					Std. deviation		0.677
					Minimum		2
					Maximum		5
					Range		3
					Interquartile range		1
					Skewness		-0.929
					Kurtosis		1.123
							0.251
							0.498

*The above tables were produced by the use of a dataset for my research on migrants' social inclusion

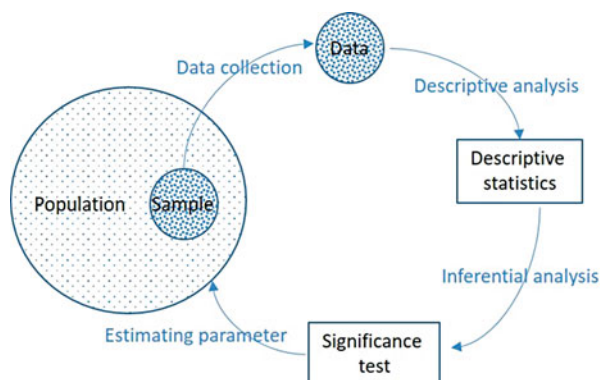
measurement, a variety of statistics of central tendency and dispersion are producible to describe the distribution of the sample.

The central tendency is "an estimate of the centre of a distribution of values" (Trochim and Donnelly 2007, p. 266), and there are three types of central tendency: mean, median, and mode. Dispersion or variability refers to the spread of the values around the central tendency, and the common statistics of dispersion include the range, variance (standard deviation), minimum, maximum, and quartiles. Checking the shape of distribution through skewness (the degree of symmetry of the distribution) and kurtosis (the degree of pointiness of the distribution) is also part of descriptive analysis.

Although descriptive analysis generally examines single variable, it can also involve two variables to explore their relationship. For instance, the left table in Table 4 is an outcome of univariate descriptive analysis of life satisfaction, whereas the right table shows a relationship between gender and the life satisfaction. Cross-tabulation that explores the relationship between two categorical variables is also a type of descriptive analysis.

While descriptive analysis seeks to simply describe the sample, inferential analysis aims to reach conclusions that extend beyond the description of the sample (Trochim and Donnelly 2007). Literally, inferential analysis infers from the sample data of the population, the entire pool from which a statistical sample is drawn. Usually, quantitative research deals with the sample data except for the Census and

Fig. 1 Flow chart of inferential analysis



tries to estimate the parameters, a measurable characteristic of a population, from the sample statistics. Thus, the purpose of inferential statistical analysis is to generalize the findings from the sample data into the wider target population (Babbie 2016). Inferential analysis is usually the final phase of data analysis (Grove et al. 2015).

The process of generalization in inferential analysis requires a test of significance. Significance test tells the researcher the likelihood that the sample statistics can be attributed to sampling error. In other words, significance test enables informed judgment about if the observation found in the sample data occurred by chance and how confident the researcher can be in generalizing the sample outcomes. It should be noted that no sample data perfectly represents the population and guarantees accurate estimates for generalization. Significance test defines the confidence level of the estimates to the researcher.

In statistics, the level of confidence is expressed in probability such as 95%, 99%, or 99.9%. They can alternatively be expressed in probability values such as 0.05, 0.01, or 0.001. In social and behavioral sciences, 95% confidence level is commonly applied. If a significance test satisfies the criterion of 95% of confidence, it is regarded that the researcher can get the same sample statistics from 95 times of repeated sample surveys out of 100 times. In univariate statistics, the accuracy of the sample statistics is expressed in range. For instance, when the sample size is 1,000 and the 95% confidence level is applied, the population parameter is approximate estimated to be within the range of plus or minus sampling statistics (Babbie 2016) (Fig. 1).

Despite some possible flaws and criticism (Armstrong 2007), inferential data analysis relies on the custom of significance test for generalization. Test of statistical significance is a “class of statistical computations that indicate the likelihood that the relationship observed between variables in a sample can be attributed to sampling error only” (Babbie 2016, p. 461). Significance test starts with setting up a null hypothesis and an alternative hypothesis. They are also known as a statistical hypothesis and a research hypothesis (Grove et al. 2015). Null hypothesis predicts there is no relationship between variables tested in the analysis (Grove et al. 2015). It assumes that there is no predicted effect of the experimental manipulation (Field 2013). In univariate statistics, it suggests that the sample statistics is the same as the

population parameter. Alternative hypothesis is contrary to null hypothesis and assumes that certain variables in the analysis will relate to each other. Significance test enables a judgment if the null hypothesis is rejected or not.

In the decision-making of adopting or ejecting the null hypothesis, the significance value, also known as *p*-value, is used (*p* represents probability). Every inferential analysis produces significance values, and the research interprets the outcomes against the α (alpha)-level. α -Level is a cutoff criterion for statistical significance and usually sets at 0.05 (95% significance level) or 0.01 (99% significance level). If the *p*-value is greater than the α -level, the outcome is regarded as “statistically not significant,” and the researcher rejects the alternative hypothesis and adopts the null hypothesis. In other words, “significant at the 0.05 level ($p \leq 0.05$)” means that the probability that a relationship observed in the sample analysis occurs by the sampling error in no more than 5 in 100 (Babbie 2016).

4 Conducting Data Analysis

4.1 Choice of a Suitable Analysis Model

Each analysis model has been designed to serve different type of research questions, analysis purposes, and the level of measurement of the variables included in the analysis. Table 5 summarizes the appropriate analysis model by the nature of research question and the variable requirements. It should be noted that the analysis models presented in the table are only the samples of all the different models. It is suggested that researchers should refer to the manual texts to choose the most suitable model. More detailed information for decision-making trees are available in the following references (Hair et al. 2006; Grove et al. 2015; Pallant 2016).

There is a range of software available for statistical analysis. While some software is designed for specialized purposes such as LISREL or AMOS for structural equation modeling, one of the most commonly used software in social and behavioral sciences is Statistical Package for Social Sciences (SPSS) and Statistical Software Analysis (SAS). Excel also has capacity for statistical analysis, but it requires additional processes for inferential statistics compared with statistical software.

4.2 Practice of Data Analysis in Quantitative Research

Although each analysis model produces different statistics, they generally share the structure of outcomes. That is, statistical analysis usually presents descriptive statistics first and then proceeds to the outcomes of significance test. This section will demonstrate an example of an inferential data analysis using the ANOVA model, which explores the mean difference between more than two groups. The ANOVA requires one nominal variable as a grouping variable and one test variable measured at a scale level that can produce the mean. The following examples are the products

Table 5 Statistical analysis and the requirements

Research question	No. of variable	Level of measurement	Analysis model	Analysis purpose
Exploratory	Single	Nominal	Frequency percentage	Descriptive
		Scale	Central tendency, dispersion, distribution	Descriptive
			z-test/one sample t-test	Inferential
Relational (general)	Two	Nominal	Cross-tabulation	Descriptive
			χ^2 (chi-square) goodness of fit	Inferential
		Ordinal ^a	Spearman's ρ (<i>roh</i>)	Inferential
		Scale	Bivariate correlation (Pearson's correlation)	Inferential
	Multiple	Scale	Factor analysis	Inferential
			Structural equation model	
Relational (group comparison)	Two	Nominal (grouping variable)/scale (test variable)	Independent samples t-test	Inferential
			One-way analysis of variance (ANOVA)	
	Multiple		Multivariate analysis of variance (MANOVA)	Inferential
Causal	Two	Nominal (grouping variable)/scale (test variable)	Repeated measures ANOVA	Inferential
		Scale	Simple linear regression	Inferential
	Multiple	Scale	Multiple regression	Inferential
			Path analysis	

^aOrdinal variables are sometimes difficult to deal with in statistical analysis because of its in-between nature. They have been sometimes accepted to the data analysis for scale measurements in social sciences. However, analysis models have been developed to more properly deal with them, and now nonparametric alternative models for ordinal variables are available for most cases (Pallant 2016)

of SPSS. The dataset was from my recent pilot study of social inclusion of migrants in Australia.

The research question to be examined in this analysis is if perceived life satisfaction of migrants is related to their visa status. The null hypothesis of this analysis is that all of the groups' population means are equal. The alternative hypothesis is that the mean is not the same for all groups or there is at least one group whose mean differs from all of the others.

The first sub-table in Table 6 provides descriptive statistics of each groups and the whole sample. From this table, an overview idea about the mean difference by different groups is obtained. Obviously, the sample statistics show that citizenship holders present the highest level of life satisfaction and the temporary visa holders

Table 6 Outcomes of ANOVA

Descriptives								
Overall satisfaction with life								
	N	Mean	Std. Deviation	Std. Error	95% confidence interval for mean		Minimum	Maximum
					Lower bound	Upper bound		
Temporary	12	3.50	0.798	0.230	2.99	4.01	2	5
Permanent	62	3.60	0.664	0.084	3.43	3.77	2	5
Citizen	77	3.95	0.705	0.080	3.79	4.11	2	5
Total	151	3.77	0.716	0.058	3.65	3.88	2	5

Test of homogeneity of variances

Overall satisfaction with life

Levene statistic	Df1	Df2	Sig.
1.998	2	148	0.139

Significance test for equal variance across groups

Anova

Overall satisfaction with life

	Sum of squares	Df	Mean square	F	Sig.
Between groups	5.176	2	2.588	5.341	0.006
Within groups	71.712	148	0.485		
Total	76.887	150			

Significance test for mean difference between all groups

Multiple comparisons

Dependent variable: overall satisfaction with life

tukey hsd

(I) visa status group	(J) visa status group	Mean difference (i-j)	Std. error	Sig.	95% confidence interval	
					Lower bound	Upper bound
Temporary	Permanent	-0.097	0.220	0.899	-0.62	0.42
	Citizen	-0.448	0.216	0.099	-0.96	0.06
Permanent	Temporary	0.097	0.220	0.899	-0.42	0.62
	Citizen	-0.351*	0.119	0.010	-0.63	-0.07
Citizen	Temporary	0.448	0.216	0.099	-0.06	0.96
	Permanent	0.351*	0.119	0.010	0.07	0.63

Significance test for mean difference within each pair of

*. The mean difference is significant at the 0.05 level.

have the lowest mean. However, it is a wrong interpretation if it is concluded that life satisfaction is actually different by visa status among all migrants in Australia. This is because the descriptive outcomes are immediate statistics of the sample data.

The second sub-table is an outcome of a test for equal variance between groups. The group comparison models assume that the variances are the same across the groups. This is because if the variances are unequal, it can increase the possibility for the incorrect rejection of a true null hypothesis (Type I error) (there are two types of error involved in

decision-making in significance test. Type I error occurs when the null hypothesis is rejected when it is true. On the contrary, Type II error occurs when the null hypothesis is adopted when it is false. The risk of errors is indicated by the level of significance. That is, there is a greater risk of a Type I error with a 95% significance ($\alpha = 0.05$) level than with a 99% significance level ($\alpha = 0.01$). Conversely, the risk of a Type II error is greater increases when the significance level is 99% than when it is 95% (Grove et al. 2015)). If the Sig. value (p -value) is greater than 0.05, the assumption of homogeneity of variances is not violated (the null hypothesis for equal variance is accepted). As the p -value is greater than 0.05 in this case, it is safe to move on to the next table.

The last sub-table presents significance test of the mean difference. It is by this table that a conclusion is made about the mean difference of the population. The F-value means variance of the group means divided by the mean of the within group variances. The detailed logic and the equations for between groups and within groups sums of squares and the calculation of the F-value can be found in (Tabachnick and Fidell 2013) and many other texts. As the p -value of the ANOVA is less than 0.05, the alternative hypothesis is adopted, which means that at least one group has a statistically significantly different mean.

Although statistically significant mean difference was observed in the ANOVA table, it is still not certain about which group has a significantly different mean. The last sub-table of post hoc test shows the results of mean comparisons of each combination, through which the pair where the significant mean difference occurred is identified. According to the outcomes, Citizen group has a significantly higher mean than Permanent group ($p \leq 0.05$), whereas mean difference between Temporary and Permanent groups is not significant ($p \geq 0.05$).

5 Conclusion and Future Directions

This chapter was designed to provide introductory understandings of quantitative data analysis. A special focus was given to the considerations in the choice of appropriate data analysis model and the process of quantitative data analysis. It is admitted that this chapter was unable to cover diverse range of analysis models. However, this chapter provided understandings of key concepts that underpin across quantitative data analysis.

In consideration of the statistical understandings of intended readers at beginner or intermediate levels, this chapter took a conceptual approach rather than a formulaic approach, avoiding explaining by the involvement of the numerical equations. Thus, it is suggested that readers who intend to verify the conceptual understandings through mathematical formula refer to other statistical manuals. Despite limitations, it is hoped that this chapter provided a useful guide for conducting quantitative analysis.

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Reporting of Qualitative Health Research

55

Allison Tong and Jonathan C. Craig

Contents

1	Introduction	972
2	The Problems in the Reporting of Qualitative Health Research	973
3	The Challenges of a Standardized Approach to Reporting Qualitative Research	974
4	Reporting Guidelines for Qualitative Research	975
5	Reporting Qualitative Health Research	977
5.1	Research Team and Reflexivity	978
5.2	Methodology	978
5.3	Participant Selection and Description of the Sample	978
5.4	Data Collection	979
5.5	Data Analysis	980
5.6	Study Findings	981
6	Conclusion and Future Directions	982
	References	982

Abstract

Transparent and comprehensive reporting can improve the reliability and value of research. Reporting guidelines have been developed for different quantitative research designs including CONSORT for randomized controlled trials, STROBE for observational studies, and PRISMA for systematic reviews. Only a few reporting guidelines are available for qualitative studies – such as the

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Consolidated Criteria for Reporting Qualitative Health Research (COREQ), which includes reporting items that address the research team and reflexivity, methodological framework, data collection, data analysis, and presentation of the findings. This chapter will address the current problems in reporting qualitative research, discuss the challenges of a standardized approach to reporting qualitative research, provide an overview of current reporting guidelines, propose principles for reporting the methods and findings of qualitative studies, and discuss strategies to improve the quality of reporting of qualitative health research.

Keywords

Qualitative research · Reporting guidelines · Quality · Publishing · Interviews · Focus groups

1 Introduction

Health and medical research aims to generate knowledge to improve healthcare and outcomes for people. However, the lack of transparency of reporting research studies can diminish the value and reliability of research because readers and potential users cannot assess the validity and relevance of the study (Simera et al. 2010). Consequently, this leads to “research waste” (Glasziou et al. 2014). The problem of poor reporting of research is pervasive and long-standing and perhaps has been made more evident with the increasing number of systematic reviews (Simera et al. 2010; Moher et al. 2014; Altman and Simera 2016). Systematic reviews of quantitative and qualitative studies consistently show incomplete, variable, and generally poor reporting across the primary studies included in the review (Altman and Simera 2016).

The International Committee of Medical Journal Editors has emphasized that “the research enterprise has an obligation to conduct research ethically and to report it honestly” (DeAngelis et al. 2004, p. 606). Reporting guidelines for research help to improve the clarity about the study design, methods, and process so readers and potential users of the research can understand, replicate, appraise, translate, and implement the findings. In 2006, the Enhancing the Quality and Transparency of Health Research (EQUATOR) Network was established to “improve the reliability and value of published health research literature by promoting transparent and accurate reporting and wider use of robust reporting guidelines” (Altman and Simera 2016, p. 2). There are approximately 400 reporting guidelines listed in the EQUATOR Network Library (<http://www.equator-network.org/>). The past decade has also seen an increase in the number of journals that endorse or mandate the use of reporting guidelines (Stevens et al. 2014).

Many reporting guidelines have been produced for different types of quantitative studies including the Consolidated Standards for Reporting Trials (CONSORT) statement for randomized trials, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement for observational studies, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews, and the Standards for Reporting

Diagnostic Accuracy Studies (STARD) for diagnostic accuracy studies (see ► Chaps. 56, “Writing Quantitative Research Studies,” and ► 59, “Critical Appraisal of Quantitative Research”). For qualitative health research, reporting guidelines also exist. The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) was developed for interview and focus group studies (Tong et al. 2007), the Standards for Reporting Qualitative Research: A Synthesis of Recommendations (SRQR) was developed for primary qualitative studies (O’Brien et al. 2014), and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement was developed for reporting the systematic review and synthesis of qualitative health research (Tong et al. 2012). These guidelines for reporting qualitative health research will be covered in more detail later in this chapter.

This chapter will cover reporting of qualitative health research, with a particular focus on reporting in peer-reviewed journal articles as this is perhaps the most common and traditional approach to disseminating health research. Specifically, this chapter will address the current problems in reporting qualitative research, discuss the challenges of a standardized approach to reporting qualitative research, provide an overview of current reporting guidelines, propose principles for reporting the methods and findings of qualitative studies, and discuss strategies to improve the quality of reporting of qualitative health.

2 The Problems in the Reporting of Qualitative Health Research

The problems in reporting the methods and findings are most evident in systematic reviews of qualitative studies, which have consistently shown variability in the quality of reporting of the included studies with many details about the research process lacking (see also ► Chap. 45, “Meta-synthesis of Qualitative Research”).

A systematic review and synthesis of 16 studies on the experiences of parents caring for children with chronic kidney disease found that important details were not provided in most studies (Tong et al. 2008). None of the studies provided the interview guide or questions, and across all studies, sparse details were provided on the methods used for data analysis. In a thematic synthesis of qualitative studies that included 30 studies involving 1552 bone marrow and peripheral blood stem cell donors on their motivations, experiences, and perspectives of donation, 19 (63%) studies specified the participant selection strategy, 2 (7%) reported the use of software to facilitate data analysis, and 20 (67%) provided participant quotations to support the findings (Garcia et al. 2013). Similarly, a recent thematic synthesis of 26 studies on patients’ perspectives and experience of living with systematic sclerosis found that only half of the studies described the participant selection strategy, methods of recording data (audio or visual recording) were reported in 18 (70%) of studies, and quotations were provided in 20 (77%) of the studies (Sumpton et al. 2017).

3 The Challenges of a Standardized Approach to Reporting Qualitative Research

The lack of transparency in published qualitative studies highlights the need to improve reporting, which may be achieved by establishing guidance or standards for reporting qualitative health research. While establishing standards for rigor remains highly contentious (Mays and Pope 2000; Yardley 2000; Barbour 2001; Dixon-Woods et al. 2004; Cohen and Crabtree 2008; Dalton et al. 2017), there is growing recognition and agreement of the need for clarity and completeness of reporting so that readers can appraise the study and assess the transferability of the findings to their setting (Tong et al. 2007; Cohen and Crabtree 2008; Dunt and McKenzie 2012; O'Brien et al. 2014). In fact, proposed quality criteria or characteristics of good qualitative research usually include transparency of the methods and findings (Yardley 2000; Cohen and Crabtree 2008). Despite this, there has not yet been any consensus on reporting items for qualitative health research (Moher et al. 2014).

There are some potential conceptual and practical challenges to acknowledge in establishing or following standards of reporting of qualitative research (Moher et al. 2014). Qualitative research is an umbrella term for a wide array of methodologies and methods, and so developing a single set of criteria that considers all the different approaches and findings may be difficult to achieve (Yardley 2000). There are also concerns that a prescriptive framework may inadvertently “reduce qualitative research to a list of technical procedures and result in ‘the tail wagging the dog’” (Barbour 2001). Also, qualitative data (e.g., transcription of interviews, videos, images, field notes, artifacts) are diverse, detailed, and nuanced, and may be presented in different ways depending on the type and nature of the data collection, and also the target audience. This can also add complexity in reporting qualitative research. Also, in view of the increasing number of qualitative articles published in biomedical journals, the limited word count also pose a challenge given the thick and detailed description of the methods and findings to be described in an article reporting qualitative research.

With these things considered, there is still a need for qualitative research to be systematically, completely, and carefully documented so that readers can assess the trustworthiness and rigor of the findings. Of particular relevance, *dependability* is the extent to which the research process is logical, auditable, and transparent and refers to coherence across the methodology, methods, data, and findings, which reiterates the case for clear and transparent reporting (Liamputtong 2013).

Reporting guidelines can improve the clarity, accuracy, and transparency of reporting and should be used as appropriate such that it does not constrain researchers in conveying the richness, meaning, and nuances in the findings from qualitative studies. It should be clarified that reporting guidelines for not purport that a specific reporting item, e.g., “use of software” improves the quality of the study given the lack of empiric basis to make this claim, but instead the reporting item is intended to make the research process more transparent and “auditable.”

4 Reporting Guidelines for Qualitative Research

While there are many resources and guidelines available for presenting qualitative research (Wolcott 2009) and assessing the conduct of qualitative studies, guidelines have also been developed specifically for the reporting of qualitative health research. Three reporting guidelines for qualitative health research are recommended for use by the EQUATOR Network (Tong et al. 2007, 2012; O'Brien et al. 2014), which will be discussed in this section.

The COREQ checklist is a reporting guideline to support explicit and comprehensive reporting of interviews and focus group studies (Tong et al. 2007). The reporting items were generated based on a comprehensive review of 22 different checklists that were identified in systematic reviews of qualitative studies, author and reviewer guidelines of medical journals, and existing checklists used to appraise qualitative studies. The items from these checklists were extracted and compiled into a complete list. Items that were duplicative, ambiguous, and impractical to assess were removed. Two new items considered relevant for reporting qualitative research that were not explicitly addressed in previous checklists were added; these were identifying the authors involved in data collection and reporting the presence of nonparticipants during data collection, for example, if others were present at the interview or focus groups. The final COREQ checklist comprises 32 criteria grouped into 3 domains: research team and reflexivity, study design, and data analysis and reporting. The COREQ reporting items for participant selection, with descriptors, are shown in Table 1.

So far, COREQ is endorsed and recommended for use in authorship policies of many general and discipline-specific journals including *BMJ Open*, *PLOS One*, *BMC*, *Palliative Care*, *Scandinavian Journal of Work, Environment and Health*, *Transplantation*, *The American Journal of Kidney Disease*, *Peritoneal Dialysis International*, *Journal of Graduate Medical Education*, *Physiotherapy*, *Journal Psychiatric and Mental Health Nursing*, *American Journal of Occupational Therapy*, *Journal of Emergency Nursing*, *British Journal of General Practice*, and the *Journal of the Academy of Nutrition and Dietetics*, among others.

The Standards for Reporting Qualitative Research (SRQR) was also developed to define standards for the broad spectrum of primary qualitative research (O'Brien

Table 1 COREQ checklist – an example reporting items for participant selection

No	Item	Guide questions/description
Participant selection		
10	Sampling	How were participants selected? For example, purposive, convenience, consecutive, snowball
11	Method of approach	How were participants approached? For example, face-to-face, telephone, mail, email
12	Sample size	How many participants were in the study?
13	Nonparticipation	How many people refused to participate or dropped out? Reasons?

Reference for the full guideline: (Tong et al. 2007)

Table 2 SRQR checklist – an example reporting item for participant selection

No	Item	Guide questions/description
S9	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^a

Reference for the full guideline: (O'Brien et al. 2014)

^aThe rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together

et al. 2014). Similarly, the authors searched for guidelines, reporting standards, and criteria for critical appraisal of qualitative studies, to generate and refine a set of items deemed important to include in guideline. The SRQR includes 21 items that cover title and abstract, introduction, methods, results/findings, and discussion. The SRQR reporting item for sampling strategy is shown in Table 2.

The SRQR has also been recommended by journals including the *British Journal of Dermatology* and *Archives of Physical Medicine and Rehabilitation*.

ENTREQ is a reporting guideline for the synthesis of multiple primary qualitative studies (Tong et al. 2012). The synthesis of findings from qualitative studies brings together evidence from different populations and healthcare contexts to provide more comprehensive information to generate new theoretical or conceptual models, to identify knowledge gaps, inform the design or primary studies, and to inform practice and policy (Thomas and Harden 2008; Ring et al. 2011). There are a range of methods to synthesize the findings, with the more common methods being thematic synthesis, meta-ethnography, critical interpretive synthesis, and narrative synthesis (Ring et al. 2011; Tong et al. 2012). Although this is an emerging type of research synthesis, they are increasingly being published and regarded as important evidence to support practice and policy (see also ► Chap. 45, “Meta-synthesis of Qualitative Research”). To develop the ENTREQ checklist, guidance and reviews relevant to the synthesis of qualitative research, methodology articles, and published syntheses of qualitative studies were identified. Reporting items were generated inductively. The preliminary ENTREQ framework was piloted against 40 published systematic reviews and/or syntheses of qualitative studies that spanned a range of time of publication, health topics, and methodology, to ensure that it could be broadly applied. The ENTREQ checklist comprises 21 items classified into five domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of the findings. As an example, the ENTREQ reporting items for the search, screening, and selection of primary qualitative studies are provided in Table 3.

Thus far, the ENTREQ checklist has also been included in authorship policies of peer-reviewed journals including *Australian Critical Care*, *British Journal of Dermatology*, *Journal of the Academy of Nutrition and Dietetics*, *International Journal*

Table 3 ENTREQ checklist – an example reporting items for the search, screening, and selection of primary qualitative studies

No	Item	Guide questions/description
3	Approach to screening	Indicate whether the search was preplanned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until the theoretical saturation is achieved)
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g., in terms of population, language, year limits, type of publication, study type)
5	Data sources	Describe the information sources used (e.g., electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), gray literature databases (digital thesis, policy reports), relevant organizational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches were conducted; provide the rationale for using the data sources
6	Electronic search strategy	Describe the literature search (e.g., provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena-related terms, filters for qualitative research, and search limits)
7	Study screening methods	Describe the process of study screening and sifting (e.g., title, abstract and full text review, number of independent reviewers who screened studies)

Reference for the full guideline: (Tong et al. [2012](#))

of Surgery, European Journal of Oncology Pharmacy, Palliative Medicine, American Journal of Kidney Disease, and Transplantation.

In 1999, Elliot and Fischer proposed guidelines for the publication of qualitative research studies in psychology and related fields. In addition to providing guidelines applicable to both quantitative and qualitative approaches, they specified seven reporting items particularly pertinent to qualitative research: owning one's perspective, situating the sample, grounding in examples, providing the credibility checks, coherence, accomplishing general versus specific research tasks, and resonating with readers. Each of these is accompanied by a discussion and examples of poor practice and good practice. Overall, the principles put forward by the authors are covered in the reporting guidelines recommended by the EQUATOR Network.

5 Reporting Qualitative Health Research

This section will broadly outline some principles and suggestions for reporting key aspects and stages of qualitative research including research team and reflexivity, methodology, participation selection, data collection, data analysis, and study findings. The section will largely draw from existing reporting guideline outlines in the previous section of this chapter, with examples provided from a range of published qualitative studies.

5.1 Research Team and Reflexivity

As qualitative researchers are intrinsic to the research process and inevitably bear influence on all aspects of the study including data collection and analysis, there is a need to report details about the research team. Reflexivity involves reflection and documentation of how the background, motivations, assumptions, actions, or intentions of the researchers may have impacted the product of the research investigation (Yardley 2000). Any relevant preestablished relationship between the researchers and participants may be important to acknowledge if it influences rapport with participants. For example, a physician interviewing their own patients may inhibit honest and open responses.

5.2 Methodology

The methodology guides the approach to data collection and analysis, which should be stated if a specific methodology was used in the study. The examples of qualitative methodologies listed in COREQ include grounded theory, discourse analysis, ethnography, and phenomenology (Tong et al. 2007). However, there are other methodological frameworks that qualitative researchers may situate their research within. These include feminist methodology, symbolic interactionism, postmodernism, and participatory research (Liamputtong 2013).

5.3 Participant Selection and Description of the Sample

The selection of participants should be described in terms of the strategy and rationale as this can allow readers to ascertain the appropriateness of the sample to the research question, the range of perspectives obtained, and the extent to which the data elicited from the sample is transferable to other settings (Kuper et al. 2008; Anderson 2010; Moher et al. 2014). Sampling strategies may be determined based on the specific methodology used, but strategies that are commonly reported in qualitative research publications include:

- Purposive sampling, to select participants who can provide a rich and meaningful data pertinent to the research questions (key informants) and may involve various approaches including typical case sampling to select the usual cases of a phenomenon; maximum-variation sampling to obtain the widest range of perspectives as possible, i.e., based on demographic or clinical characteristics, in order to obtain a broad range of data; and deviant case sampling to select the most extreme case of a phenomenon (Giacomini and Cook 2000; Kuper et al. 2008; Patton 2015). Also, theoretical sampling is a type of purposive sampling used in grounded theory whereby participants are chosen based on the theories that emerge from the concurrent data analysis (Bryant and Charmaz 2010).

- Convenience sampling, to select participants who are easily accessible (Liamputtong 2013).
- Snowball sampling, to ask participants to suggest other potential participants who can offer a different and relevant perspective, or to access hard to reach populations (Liamputtong 2007, 2013).

The sample size and characteristics of the participants should also be reported. For focus groups, specifying the number of focus groups and the number participants in each group may allow readers to determine whether “enough” focus groups were convened for each stratum of investigation (if any) and the extent to which participants were given opportunity to express their opinion.

Also, the number of those who did not participate in the study and the reasons for nonparticipation should be stated, as this may have relevant implications for the findings that readers may need to consider in assessing the transferability of the data to their context and population (Tong et al. 2007). Examples of reporting items for participant selection are shown in Tables 1 and 2 in the previous section.

5.4 Data Collection

The setting, mode, and techniques of data collection can have an impact on the findings, and it is important that these are carefully described in a qualitative study (Graffigna and Bosio 2006; Kuper et al. 2008; Irvine 2011). These aspects are addressed in the COREQ (Tong et al. 2007) and SRQR (O’Brien et al. 2014) reporting guidelines and discussed in the following section.

In terms of the setting, data collection may occur in the participants’ home, workplace, or in the clinic. However, patients may feel intimidated, disempowered, and less inclined to express their views honestly and freely if the research interviews are conducted in a clinical setting.

There may also be differences in the data collected through face-to-face, telephone, or online interviews, and thus the mode of data collection should be stated. There are various approaches to collecting qualitative data including unstructured or semi-structured interviews, focus groups, documents (journals, online, and digital media), and observations (see ► Chaps. 23, “Qualitative Interviewing,” ► 24, “Narrative Research,” ► 25, “The Life History Interview,” ► 26, “Ethnographic Method,” ► 27, “Institutional Ethnography,” ► 28, “Conversation Analysis: An Introduction to Methodology, Data Collection, and Analysis,” ► 29, “Unobtrusive Methods,” ► 30, “Autoethnography,” ► 31, “Memory Work,” ► 32, “Traditional Survey and Questionnaire Platforms,” ► 33, “Epidemiology,” ► 34, “Single-Case Designs,” ► 35, “Longitudinal Study Designs,” ► 36, “Eliciting Preferences from Choices: Discrete Choice Experiments,” ► 37, “Randomized Controlled Trials,” and ► 38, “Measurement Issues in Quantitative Research”). The specific method (or methods) of data collection used in the study should be reported.

For interviews and focus groups, the question guide and prompts should be provided so readers can assess whether the focus and scope of the questions align with the

research aims and whether they were appropriate in allowing participants to convey their opinions on their own terms (see ► [Chap. 23, “Qualitative Interviewing”](#)). For journal publications, this may be published as an online supplementary file.

There may also be other relevant aspects to report depending on the population. For example, studies involving children may need to report how the methods were age-appropriate and considered their developmental and communication needs (Ireland and Holloway 1996; Punch 2002; see also ► [Chap. 115, “Researching with Children”](#)). It may also be relevant to report the language in which the interview was conducted if participants were non-English speaking and the study is reported in English language as linguistic nuances and cultural meaning may be potentially lost or diluted if the data were not collected in the primary language of the participants (Twinn 1997; Esposito 2001; Liamputtong 2010; see also ► [Chaps. 94, “Finding Meaning: A Cross-Language Mixed-Methods Research Strategy,”](#) and ► [95, “An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups”](#)).

The method for recording the participant’s perspectives should also be detailed, with audio-recording and transcription generally regarded as the “best practice” approach to accurately capture verbal data rather than relying on the researchers’ notes or memory. Otherwise, reasons for not recording the collection of data should be provided. For example, participants who are asked to give opinions on very sensitive topics may not give permission to be recorded, and thus, it would not be ethical to audiotape them. It is also relevant to state if data collection, usually interviews, was conducted prospectively as this may contribute to rapport and richness of the data collected. Whether field notes were used to capture nonverbal communication and the contextual details surrounding data collection should also be reported (Popay et al. 1998).

The duration of data collection (e.g., length of the interview, or time frame of the observation, and length of the recorded clinical consultation) allows readers to gauge the extent of data collection.

Data saturation occurs when little or no new information or concepts are being identified in subsequent data collection (Mays and Pope 2006; Kuper et al. 2008; Liamputtong 2013). The intention, definition, and extent to which this was achieved should be stated or discussed so readers can consider whether it was adequate to enable comparisons of shared and divergent perspectives, experiences, and meanings related to the topic of inquiry.

5.5 Data Analysis

There are many accepted approaches to analyzing qualitative data, which should be clearly detailed (Bradley et al. 2007; Kuper et al. 2008). The number of investigators and their involvement in the different stages of analysis (e.g., independent coding, feedback on the preliminary analysis) should be reported. For example, it may be more defensible to report the use of investigator triangulation to reassure readers that the complete range and depth of the data

collected have been captured in the findings and are not just a reflection of the agenda or assumptions of a single researcher. Researchers should describe the process for identifying, defining, and interpreting the data, including how concepts were identified and coded, how concepts were grouped together, the development of the coding tree, and the derivation of the themes (if applicable) (see ► Chaps. 48, “Thematic Analysis,” ► 49, “Narrative Analysis,” and ► 50, “Critical Discourse/Discourse Analysis”). Any software packages to manage retrieve and store qualitative data should be reported, as the use of software may facilitate a systematic and traceable coding process (Anderson 2010; see ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). Researchers should also state whether member checking was carried out, in which the preliminary findings are sent to the participants for further feedback, comment, and integrated into the final analysis (Liamputtong 2013).

The COREQ reporting items for data analysis include number of data coders, description of the coding tree, derivation of themes, use of software, and participant (member) checking (Tong et al. 2007). Similarly, the reporting items in the SRQR include data processing (methods for processing the data before and during the analysis, i.e., transcription, data management and security, verification of data entry, coding), data analysis (process by which inferences, themes, and so on were identified and developed, including the researchers involved in the data analysis, reference to a specific methodology if relevant, and the rationale), and techniques to enhance trustworthiness (e.g., member checking, audit trail, triangulation) and the rationale (O’Brien et al. 2014).

5.6 Study Findings

Researchers conducting qualitative studies have a responsibility to “construct a [convincing] version of reality” that readers can recognize to be meaningful to them (Yardley 2000). The findings of the qualitative study need to be described in a comprehensive and compelling way such that it captures the richness, depth, and context of the data to provide insights pertinent to the research question. There is also a need to demonstrate, to some degree, the transferability of the findings to other populations and settings.

The synthesis and interpretation may be presented in different ways, for example, as a set of themes or a theory or model (Bradley et al. 2007). The presentation of the findings or output depends on the methodology or methods used. For example, a qualitative study using thematic analysis should report themes; or a grounded theory study would be expected to describe theory grounded in the participants’ perspectives.

The COREQ (Tong et al. 2007) and SRQR (O’Brien et al. 2014) guidelines both recommend providing a link between the findings and empirical data. Providing raw data, i.e., quotations and images, can strengthen the confirmability of the research findings as this can allow readers to evaluate the consistency between the data presented and the findings of the study (Lincoln and Guba 1985). Providing quotations from a range of participants is recommended so researchers can enhance the

transparency and trustworthiness of their findings and interpretations of the data (Tong et al. 2007; O'Brien et al. 2014). Due to word count restrictions in biomedical journals, it may be necessary to present quotations in tables or as supplementary files.

6 Conclusion and Future Directions

Qualitative research encompasses a suite of different theoretical and methodological frameworks and methods for collecting and analyzing the data, and there are multiple ways in which the findings can be presented. Transparent and complete reporting of qualitative health research can help readers assess the rigor of the methods and trustworthiness of the findings and thus support the translation and implementation of findings for patients, caregivers, and health professionals, to help improve the care and health outcomes for people. Reporting guidelines can serve to help legitimize qualitative research (Elliot et al. 1999). There are reporting guidelines available for primary qualitative studies and synthesis of multiple qualitative studies, which have increasingly been endorsed and adopted by biomedical journals in an effort to improve the quality of reporting of qualitative research.

Obtaining broader consensus on reporting items to inform revisions of existing reporting frameworks, and further efforts to develop and evaluate guidelines for specific qualitative methodologies and methods, possibly as extensions to current guidelines, may help to contribute to the broader efforts in improving the quality of reporting health research.

Qualitative research can generate evidence about patients' experiences, values, and goals, to inform strategies for patient-centered healthcare. Researchers conducting qualitative studies need to report their rationale, methods, and findings in a clear, transparent, and compelling way and thereby maximize the potential uptake of the findings into practice and policy to improve quality of care and patient outcomes.

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Writing Quantitative Research Studies

56

Ankur Singh, Adyya Gupta, and Karen G. Peres

Contents

1	Introduction	986
2	Reporting Guidelines and Checklists	987
2.1	Title and Abstract: Attract Reader's Attention	987
2.2	Background/Introduction Section: Generate Interest about the Study	988
2.3	Methods/Methodology Section: Describe the Process Involved	989
2.4	Results/Findings Section: Reveal the Findings	992
2.5	Discussion Section: Relate to the Bigger Picture	993
2.6	Conclusion: Leave the Reader Enlightened	995
3	Conclusion and Future Directions	995
	References	996

Abstract

Summarizing quantitative data and its effective presentation and discussion can be challenging for students and researchers. This chapter provides a framework for adequately reporting findings from quantitative analysis in a research study for those contemplating to write a research paper. The rationale underpinning the reporting methods to maintain the credibility and integrity of quantitative studies

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is outlined. Commonly used terminologies in empirical studies are defined and discussed with suitable examples. Key elements that build consistency between different sections (background, methods, results, and the discussion) of a research study using quantitative methods in a journal article are explicated. Specifically, recommended standard guidelines for randomized controlled trials and observational studies for reporting and discussion of findings from quantitative studies are elaborated. Key aspects of methodology that include describing the study population, sampling strategy, data collection methods, measurements/variables, and statistical analysis which informs the quality of a study from the reviewer's perspective are described. Effective use of references in the methods section to strengthen the rationale behind specific statistical techniques and choice of measures has been highlighted with examples. Identifying ways in which data can be most succinctly and effectively summarized in tables and graphs according to their suitability and purpose of information is also detailed in this chapter. Strategies to present and discuss the quantitative findings in a structured discussion section are also provided. Overall, the chapter provides the readers with a comprehensive set of tools to identify key strategies to be considered when reporting quantitative research.

Keywords

Quantitative analysis · Reporting · Research methodology · Writing strategies · Empirical studies

1 Introduction

Research and scientific enquiry forms the basis for generating evidence pertaining to a specific question of interest. Quantitative data collection and analysis guided by statistical principles are common methods of choice to address key questions related to studying social and health phenomenon at the population level. Mimicking the population phenomenon within the sample through application of statistical models carefully allows researchers to generalize findings obtained from a sample to a larger population of interest.

The consistency of statistical analysis with the research question and the nature of data, along with the quality of design as well as the conduct of the study (for example: compliance with protocol), deeply impact the extent to which findings from a study can be trusted. These aspects to quantitative research are the building blocks or a basic recipe for a good study. In addition to fulfilling the fundamental requirements of appropriate scientific methods and rigor, due attention must be given to presentation of study findings. When presented inadequately, a study conducted with appropriate scientific methods and rigor can considerably limit the interest of journal editors, peer reviewers, and ultimately the readers. Given the low acceptance rates in high-quality academic journals, and more and more articles being rejected editorially even before peer review, appropriate presentation of quantitative research can substantially benefit (Szklo 2006; Kool et al. 2016). Therefore, adequate

presentation of quantitative research is central to successful publication and dissemination of study findings.

This chapter aims to provide a general and preliminary framework for consideration for both students and researchers in public health discipline, for appropriately presenting quantitative results when writing journal articles. We would caution the readers to use this chapter as a general framework for preparing quantitative research studies and also alert the readers to more closely follow specific journal and disciplinary rules/guidelines suited to their purpose as they often vary a lot in their approach and styles.

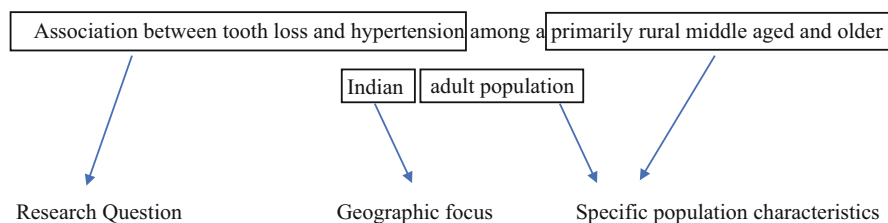
2 Reporting Guidelines and Checklists

Depending on the nature of the quantitative research (interventional or observational), reporting guidelines and checklists exist that can help researchers organize and present their information in an accurate and consistent manner. Two widely applied checklists for reporting include “STrengthening the Reporting of OBservational studies in Epidemiology” (STROBE) statement and “Consolidated Standards of Reporting Trials” (CONSORT) statements (Vandenbroucke et al. 2007, Mannocci et al. 2015). STROBE statement is applied to observational study designs including cohort, case-control, and cross-sectional studies. CONSORT statement is applied to interventional studies, mainly randomized trials (Schulz et al. 2010). Completion of these checklists during submission of articles for peer review is a requirement in many journals. These checklists can also be useful tools for critical appraisal of quantitative studies (see also ► Chap. 59, “Critical Appraisal of Quantitative Research”). Reviewers seek a structural presentation of quantitative studies to maintain a logical flow of content for readers. Most journals seek submissions that report quantitative research with relevant information structured in the form of title and abstract, keywords, introduction/background, methods, results, discussion, references, acknowledgments, and tables and figures. These sections are elaborated below to capture the minimum information they should aim to capture.

2.1 Title and Abstract: Attract Reader’s Attention

The title of the research paper is the first and foremost point of contact that the authors make with their reader. A succinct, attractive, and descriptive title brings the reader’s attention to a paper. A well-informed title also assists in proper indexation in electronic databases so that it is identified with ease by researchers (Dickersin et al. 2002). While this applies to both qualitative studies and reviews, this is critical for quantitative studies. The title of a quantitative study should ideally inform the population that it addresses the type of research design/methodology and the key question that the study is answering. These are useful aspects that inform regarding the generalizability of the study, novelty in research idea or methodology, and the relevance of the topic for the readers. Thus, the authors must explicitly state the

important identifiable aspects of their research paper. In addition to the title of the study, listing relevant *keywords* for the work presented can also assist in the indexation purposes. For example (Singh et al. 2016):



An abstract is a further elaboration of the title of the research paper, with a length of about 200–300 words, depending on the journal guidelines. Majority of the times in one paragraph, the abstract summarizes the major aspects of the paper in the following sequence: Introduction (purpose leading to aims and objectives), Methods (the study design and key information about the sample, setting, and other methods used to conduct the study), Results (the main findings of the study in the form of mean, frequency, prevalence, standard deviations, absolute and relative measures such as ratios, rates, proportions, percentages, trends, etc.), and Discussion/Conclusion (relating the results back to the aims and objectives in a summary form). Some journals request for an additional component such as implications of the research that requires the authors to state future implications of the work presented. Often, some journals prefer a nonstructured abstract where these headings are not supposed to be identified. Mostly, the abstract is the point where the reader decides whether to read the entire paper or not. Thus, it should include enough key details to enable the reader to make an informed decision (Szklo 2006).

Titles and abstracts are also critical, as they form the first criteria for selection of studies within systematic reviews (Bhaumik et al. 2015). Sometimes researchers may also cite a research paper based on the appropriateness of the abstract. Though the abstract is an opening section of any research paper, it is advised that the abstract be written at the very last to ensure that the information presented in the abstract completely aligns with the paper.

2.2 Background/Introduction Section: Generate Interest about the Study

The key purpose of the background/introduction (BI) section is to establish the context of the study being presented. Some key questions that the authors are expected to answer in the introduction section of a research paper are as follows: What is the problem? Why is it a problem? What is the strength and magnitude of the problem? Why is it important? What is already known about the topic? What are the gaps in knowledge? and how will the study contribute toward filling the gap? Summarizing the existing evidence (published literature) on the research topic of

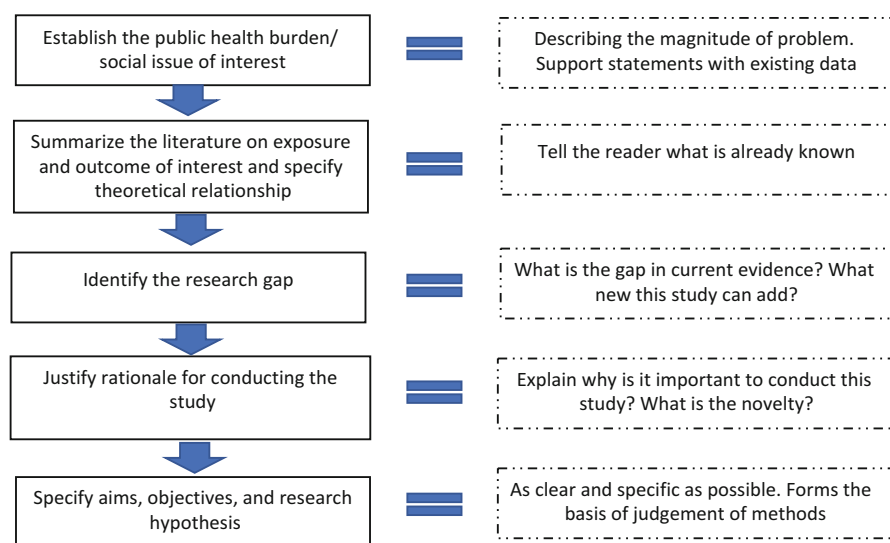


Fig. 1 Key aspects of the structure for BI

interest and providing an understanding of the magnitude of the problem being investigated can achieve this. It is the most important section to establish the plausibility of the hypothesis being tested within the study (Szklo 2006).

Writing the BI section for quantitative study can benefit by following a structure. As an example, for a journal that has a word limit of 2500–3000 words, the BI needs to be very concise so that the authors can accordingly allocate more space to the methods and discussion section. In such cases, using a structure within the BI section can enhance the logical flow while keeping the text concise and succinct (see Fig. 1).

It is advised that the BI section of the manuscript reporting quantitative findings follows an inverted funnel approach where authors start from presenting the research context from a broad overview and arrive to narrowly defined specific research objectives. However, this approach comes with a risk. By the time the readers reach specific aims of the study, the presentation of multiple related ideas to paint a general overview of research may lead to confusion among readers regarding researchers' intended research question. Therefore, consistency of material presented within the literature section to the specific research aims and objectives is paramount. This section should ideally be limited within 500–1000 words and presentation of any superfluous or irrelevant information must be avoided.

2.3 Methods/Methodology Section: Describe the Process Involved

Methods section is one of the most important components of the research paper as it enables the reader to develop confidence in the work being conducted through

transparent and reproducible methods (Szklo 2006). Consequently, authors may choose to present this section with subheadings that may include study population, study period and settings, sample selection and size and data collection, ethics consideration, study measures (outcomes, explanatory variable/s, and covariates), and statistical analysis. Reporting of sufficient and relevant information under these headings is critical. STROBE and CONSORT guidelines/checklists can be very useful to guide this process (Vandenbroucke et al. 2007, Mannocci et al. 2015). Methodological detail of a study is often absent and insufficiently described for the reviewers to judge methods for robustness and appropriateness (Kool et al. 2016). Carefully adopting the recommendations within these checklists for reporting of study design, information on participants, variables, data sources/measurement, bias, study size, and handling and categorization of quantitative variables and statistical methods can substantially make the methods section of the studies transparent and clear.

Study population and settings should identify the characteristics of the population of interest such as age group, nationality, survey purpose, and methodology if the study is a secondary analysis of already collected data. Clarity on *study settings and locations* where the data was collected is highly relevant for quantitative studies. This information on the settings and locations is crucial to judge the applicability and generalizability of the study findings. This could include the country, city if applicable, and the study environment (e.g., community, hospital, research organization). If more than one setting were used, the authors must mention each of them as appropriately as possible. Reporting other aspects of the setting (including the social, economic, and cultural environment and the climate) is critical for the readers to be able to extrapolate the results of the study to their own settings (external validity or generalizability). This is also important for guiding policy and practice (Rothwell 2005; Weiss et al. 2008).

Next, *study design* should be explicitly recognized. In quantitative research, the choice of study designs is often made at the start of the study when developing a research question and hypothesis. Study designs are broadly divided into two categories: descriptive and analytical (see Fig. 2). Descriptive studies are conducted with the aim to study the amount and distribution of the disease within a population. If the descriptive study includes individual's cases, it can be specified as a case report or a case series. Descriptive studies carried out at a population level aim to describe and summarize health and disease characteristics at the population level. The other broad category, analytical study design, is employed to study the determinants of the disease. This can be further divided into observational study and experimental study. Observation studies are further subdivided into cross-sectional studies (analytical), cohort studies, and case-control studies, while the experimental studies can be subdivided into randomized controlled trials (RCTs) and non-randomized controlled trials (non-RCTs) (see also ► Chaps. 35, "Longitudinal Study Designs," and ► 59, "Critical Appraisal of Quantitative Research"). Hence, it is very important to identify and state study design for clarity along with the rationale for choosing a particular study design over others and how best will it be able to answer the research question.

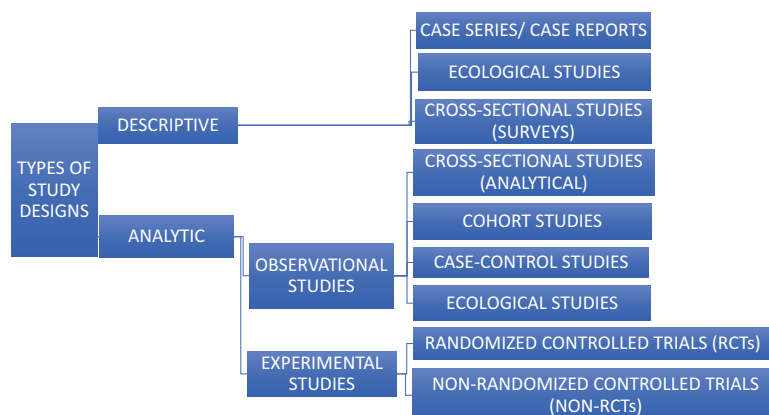


Fig. 2 Types of study designs

Data collection method describes the procedures for collecting the data for the study in sufficient detail such that the work could be replicated with minimal error if required. It is vital that the method of data collection be chosen and analyzed such that it is consistent to the study design and is best suited to answer the research question. There are a variety of techniques that can be used to collect data in a quantitative research study. These include observations, interviews, questionnaires, and so on. Information collected through these mediums are further defined as the key measures/variables for the quantitative analysis. The data can be sourced either from primary data (collected first hand) or secondary data (previously collected data). However, the types of quantitative variables that may comprise within the data could be of various types. These may include qualitative variables (binary, ordinal, nominal) and quantitative variables (discrete and continuous). These definitions should be clearly identified when describing the variables within the methods section as the choice of statistical modeling is also dependent on the types of variables. Another important aspect to be included in data collection section is to report on the explanatory and outcome variables, sample size, eligibility criteria for participants, and the description of the intervention used in the study. Participant eligibility criteria may refer to demographics, clinical diagnosis, and comorbid conditions and many others factors that make them eligible for the inclusion in the study. It is desirable to report any protocol developed prior to conducting the study that provides more detailed information on how the data was collected and any ethics approval that was sort or exempted to obtain the data for the purpose of the study.

Statistical analysis must be detailed appropriately as its consistency with the research question and the nature of the data is the keystone for any quantitative study. Statistical methods for both descriptive and inferential analysis should be informed, and the choice of statistical methods be justified by relevant text or existing references. Often, well-known statistical techniques may not require a description within the paper; instead, an appropriate reference citation may be sufficient. Choice of summary measures for describing the data, and associations,

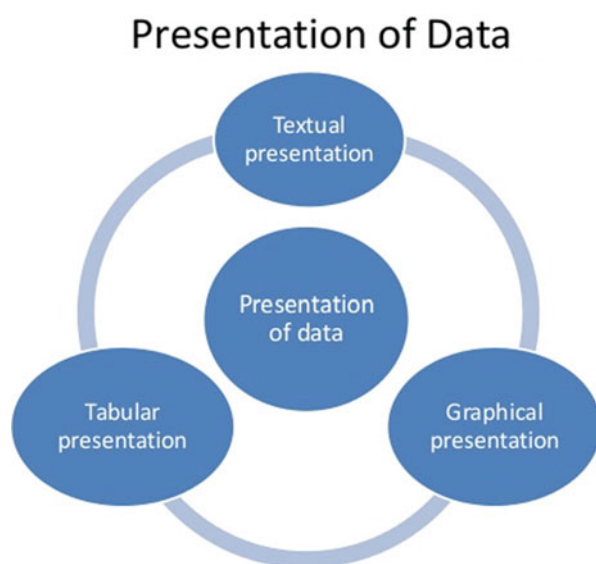
needs to be consistent with statistical analysis and can be explained at this stage. Consequently, the readers will be acquainted with the measures that they will be interpreting in the following results section. Statistical software with the versions that has been used for the analysis should also be mentioned (see also ► [Chap. 54, “Data Analysis in Quantitative Research”](#)).

A priori presentation of the theoretical model that the authors aim to follow must be explicitly declared at this stage. This is paramount as the readers gain confidence that authors are not chasing “significant” findings to publish and have a clear theoretical concept that they aim to test empirically using population-based data. A useful tool to explicitly declare an author’s position on presumed theoretical relationship between outcome, exposure, and covariates is a “directed acyclic graph” (DAG) (Greenland et al. 1999).

2.4 Results/Findings Section: Reveal the Findings

In the results section, it is important for authors to concisely and objectively present the key results, in a logical sequence using both text and illustrative materials (tables and figures) (see Fig. 3). The results section can be organized in a sequential format to present the key findings in a logical order. The text of the results section can be crafted in response to the questions/hypotheses set out in the beginning. In addition to positively toned results (significant findings), it is equally important to report the negative results. Providing a description of the missing data can help readers make cautious interpretations of the findings. Often, authors write the text of the results section based upon the sequence of tables and figures to provide clarity and flow in

Fig. 3 Different types of presenting numerical data



understanding. Most commonly, the results begin with describing the basic characteristics of the study leading to simple (crude) statistical analysis results and finally into the more complex statistical analysis results. Regardless of the complexity of the analysis employed, authors can ensure that the results are written in a simple and intelligible manner. This section includes reporting of the frequency/occurrence of various variables and their distribution in the sample, called as *frequency distribution, means, medians, and percentages* (Szklo 2006). Following this, further effect estimates in the form of differences, directionality, and magnitude between variables are reported to provide an understanding to the reader about the nature of differences or relationships observed. Few points to consider when writing the results section – avoid repetition of the values from the figures and tables in the text; only the key result or trends must be stated. It can make the tables redundant and a waste of space and energy. When reporting results in tables, authors can be more author friendly by (Weiss et al. 2008):

1. Presenting most understandable measures.
2. Appropriately presenting results of interactions, if tested.
3. Titles of tables and figures should be informative so that the readers do not need to look at corresponding text in results section.
4. Specifying units for variables.
5. Avoiding redundancy (preferably report confidence intervals than p-values, no need to present both).
6. Present results without discussing them.
7. Include specific results in the text; which are not included in tables (if this is necessary).

Text of the results section should be a summary of the key results, while tables and figures should serve to illustrate, explain, and justify this information (Kool et al. 2016). A general advice would be to ensure that the results are presented in way that interests the readers.

2.5 Discussion Section: Relate to the Bigger Picture

Discussion section is the place where the creativity and the capacity of the authors to discuss the results leading to implications are established. This is the hardest section to be written as here the authors need to convince the editor and the reader that their study is relevant and important. It ties the entire research together and offers an explanation for the bigger picture. The purpose of the discussion section is to interpret the results in the light of existing evidence on the subject. The discussion section seeks to explain a new understanding of the problem under investigation based on the obtained results. The discussion must be connected to the introduction section by way of the question(s) or hypotheses stated before and the literature cited to support that. It is not a repetition or a rearrangement of the introduction section but

instead provides a more comprehensive understanding to the problem. It is advised that the discussion section follows the following structure (Docherty and Smith 1999):

1. Statement of principal findings
2. Strengths and weaknesses of the study
3. Strengths and weaknesses in relation to existing literature. Similarities and dissimilarities with previous findings
4. A summary of the results: its plausibility, possible mechanisms explaining associations and implications
5. Unanswered questions and future research

Structuring the discussion section in this form is beneficial as it reduces overall length, prevents unjustified extrapolation and selective repetition, reduces reporting bias, and improves the overall quality of reporting (Docherty and Smith 1999). The discussion section is largely the author's playground where the author has the freedom to provide an interpretation of what the results mean in the larger context of the problem (Szklo 2006). However, speculations should be minimal and based on the findings from the study (Docherty and Smith 1999).

Strengths and limitations of the study provide the authors to display transparency and highlighted the strengths of the study alongside acknowledging any potential bias or limitation that may have affected the study findings (such as generalizability, potential bias). Strengths of the study could reflect the potential to make an important contribution in the existing pool of evidence through its rigorous data collection strategies or use of robust analytical techniques. Not every study is perfect, and there would, therefore, be some pitfalls or limitations of the study. It is necessary for the authors to be truthful and clear about the potential biases such as small sample size, low participation rate, presence of unmeasured confounders that could have affected the associations being tested, and many more depending on the context of the study. Authors should also discuss any imprecision of the results that may have arisen as a result of measurement of a primary outcome or diagnostic tool used. Perhaps the scale used was validated on an adult population but used in a pediatric one, or the assessor was not trained in how to administer the instrument.

Caution must be made to not repeat the results; instead sentences interpreting the results in a broader context are encouraged. Additionally, no new results must be presented in the discussion section; instead it must be in line with the results reported in the results section only. Uses of appropriate references to support the interpretations are another important feature of a good discussion section. If helpful, sub-headings may be used to organize the presentation of the discussion. When comparing and contrasting the findings with other published literature, the authors must ensure that they discuss reasons for similarities and differences between their and others' findings. This will allow the authors to draw a stronger argument of how their findings could be combined with existing evidence to better substantiate an understanding of the problem. The authors must ensure to cite references additional to that used in the introduction section to display the use of a wide range of evidence.

Depending on the relevance of the study, implications of the findings for research, policy, clinical care, or any other must be provided by the authors. This allows the opportunity for translating research into practice. As part of reflecting on what the findings mean, drawing out the implications of the findings for the field itself and/or societies is crucial. Contextualizing the findings within previous research helps readers to grasp the significance of the research and its contribution to knowledge. As a researcher, it is the purpose of any research conducted to offer any future implications or future recommendations (e.g., policy implications or research implications) that may benefit the society as a whole or help improvise future research.

For illustration, we use example of a published study. A paper entitled “Association between tooth loss and hypertension among a primarily rural middle aged and older Indian adult population” by Singh et al. (2016), who conducted a secondary analysis of a cross-sectional data sourced from the Longitudinal Aging Study of India. In the discussion section, the authors began by reporting the key finding of the study in line with the purpose of the study as mentioned in the last paragraph of the introduction section. The authors described the results in terms of both the direction and the magnitude of associations. This was followed by a discussion of their findings with the existing evidence highlighting both similarities and dissimilarities. Possible potential explanations were provided to support the findings that were contrary to the existing evidence. This is an important step to identify what new this study adds to the literature. The authors then highlighted the strengths of their study followed by the study’s limitations. This subsection enables the reader to view the study in confidence. After feeding the reader with all the necessary information about the study’s results, the author then drew a closure to the paper by summarizing the entire study in the conclusion section (Singh et al. 2016).

2.6 Conclusion: Leave the Reader Enlightened

In simple words, a conclusion is, in some ways, like the introduction where the author restates the research questions and summarizes key findings in line with questions. It is usually written in a single paragraph. It captures the essence of the findings of the study and provides the significance of the study findings. It is the place where the authors tie all the ends together and complete a full circle by integrating the key idea from the introduction to the key take away message from the study. The authors could end the conclusion by either making a suggestion or a recommendation or posing a question calling for an action through future investigation.

3 Conclusion and Future Directions

A scientific research paper is a piece of academic writing based on the author’s original research on a particular topic and the analysis and interpretation of the research findings. How well a research paper is written entirely depends upon its

structure, format, content, and style of writing. This is an iterative process, and it may take several drafts and even rewritings of sections to achieve coherence and consistency in the presentation of the idea, all under the word limit as instructed by the journal. Although difficult, this process has considerable value as scientific articles can lay foundations for policies and evidence-based practices and guidelines. The push on evidence-based medicine and public health practices in the last few decades has reinforced the value in generating and publishing good research.

There are profound benefits of publications in academics' research impact within the current pressures of publish or perish. Scientific publications in most academic contexts continue to play an important role in judging an individual researcher's productivity, more so at the earlier stages of academic career when applying for competitive scholarships, awards, fellowships, and jobs. Well-written scientific papers convey the capacity of researchers to deliver research independently and collaboratively to its intended audiences. Authorship statements and authorship criteria explicitly outline the independent contribution of each researcher to the complete package. It must be noted that scientific publications often take a long time from its inception to the publication stage and finally citations. Readers may find the basic principles of writing quantitative research highlighted in this chapter helpful at any stage of publication.

Ultimately, benefits of well-written scientific papers are not only limited to researchers and research teams but extend to the research community and the overall society. As authors of scientific papers, one has a key role to play in this process. The value of scientific paper writing can be best summarized by following quote from Richard Horton on the rhetoric of research (Horton 1995):

The text of a scientific paper is not an atlas that offers readers several equally appealing routes through terrain mapped out by the authors. Rather, the text describes a specific path, carefully carved by the authors, through a complex undergrowth of competing arguments. By examining this path more closely, we come to see the authors' intention and the means by which they convey this intention.

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Traditional Academic Presentation of Research Findings and Public Policies

57

Graciela Tonon

Contents

1	Introduction	1000
2	Power Mechanisms in the Scientific Field and Research Freedom	1001
3	Transmission of Research Results in the Context of Public Policy	1002
3.1	Public Policies	1002
3.2	The Relation Between Public Policies and Research Knowledge	1003
3.3	Relationship Between Researchers and Policy-Makers	1006
4	Conclusions and Future Directions	1009
	References	1010

Abstract

The transmission process of research results in the field of public policy reveals various peculiarities. In order to approach its study, it ought first to be pointed out that, in the academic field, power mechanisms have been observed, which have traditionally institutionalized certain topics and certain actors, making others invisible during the process. Furthermore, the last decades have revealed the role of politics in research production, which may be understood as a chance that the research results might be taken into account and exert an influence on public policy decisions oriented toward the people's life improvement – though this does not always happen, in practice. The aim of this chapter is to review the subject of power in the scientific field (Bourdieu, *Sociología y cultura*. México: Grijalbo,

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999

1984) and the researchers' freedom to make further progress in the definition of the concept of public policy and, on that basis, study the possible ways in which research results may be reflected in the arena of political decisions by identifying its obstacles and facilitators and proposing options to bridge the gap.

Keywords

Academic presentation · Research findings · Public policies · Knowledge

1 Introduction

The notion of universality of social knowledge greatly depends on its contextualization in time and space. Therefore, in order to be considered as scientific knowledge, its concepts must be able to build a coherent understanding of some kind of reality. However, in order to be regarded as pertinent, it ought to be attached to the reality contexts in which specific and unrepeatable events take place (Sotolongo Codina and Delgado Diaz 2006, p. 90). This necessarily gives rise to the question regarding the *forms of knowledge production* – both in the fields of strictly scientific and academic knowledge and in the participation of social and political actors, in the aforementioned production (Carrizo 2004, p. 73). Crewe and Young (2002, p. v) suggest that “research and policy defy neat separation but can be conceptually distinguished by their goals and methods: research produces knowledge, policy aims for continuity or change of a practice.”

Caplan (1979) marks a difference between conceptual use and instrumental use of knowledge. Caplan considers instrumental use to be associated with microlevel decisions, that is to say, with the day-to-day policy issues, involving administrative policy issues pertaining to bureaucratic management and efficiency, rather than substantive public policy issues. Regarding the conceptual use, Caplan (1979) describes the gradual shifts in terms of policy-makers' awareness and reorientation of their basic perspectives, which involve important policy matters and are mostly associated with macro-level decisions. On the other hand, Weiss (1991) argues that conceptual use is more common and deems as central to her enlightenment research model (Nielson 2001).

The difference between the cultural level of the professionals in government agencies and that of university researchers leads to a lack of communication between them which eventually results in low knowledge utilization (Landry et al. 2003). Thus, in order to enhance research utilization in the orbit of public policy, it is necessary to achieve a two-way exchange between both professional groups in order to integrate research findings with the policy-making process. Sharing the results of research findings with policy-makers has become a worldwide challenge (Uzochukwu et al. 2016, p. 12).

This chapter is organized by subthemes. In the first place, it will deal with the subject of power in the scientific field and freedom of research. It will later dwell on the review of the concept of public policy, on the analysis of the transmission of research results in the context of public policies – taking into account the different characteristics of knowledge and the way in which researchers and policy-makers interrelate in this field. It will finally identify and comment on the handicaps which

have historically turned up in the development of the process and the possibility of strengthening and improving it in the future.

2 Power Mechanisms in the Scientific Field and Research Freedom

The university structure has been historically based on scientific knowledge, and the science system is formulated through basic research which allows the development of knowledge while highlighting the utility and social relevance of science (Plascencia Castellanos 2006, p. 31). Yet, “the institutionalization of knowledge has brought about power mechanisms privileging certain types of research and theories which disseminate notions of truth that we finally learn, naturalize and reproduce” (Sotolongo Codina and Delgado Diaz 2006, p. 225).

Bourdieu (2000) recognizes two forms of power in the scientific field: an institutionalized political power exerted by those who actually hold decision-making positions and a specific power based on personal prestige, with a lower degree of institutionalization, exerted by invisible colleges of scientists united by mutual recognition. Bourdieu (2000) further mentions that the former type of power is achieved through political strategies which respond to the rules of bureaucratic capital, while the latter is achieved by purely accumulating science capital, solely generated by personal effort and scientific work – which explains why, in general lines, those who are most prestigious are not the most powerful.

Taking into consideration the two abovementioned situations, I stop to wonder about researchers’ actual possibilities and, most importantly, the degree of freedom they may enjoy when deciding upon their research topics (Tonon 2010a). My starting point is the idea that the only possible access to knowledge is through freedom, either built within a sociocultural research context or on the basis of each researcher’s individual achievements (Sotolongo Codina and Delgado Diaz 2006). When referring to freedom, I follow the lines of Sen (2000) who proposes that freedom should be focused on people’s possibility to become creative actors and agents of their own development. Plascencia Castellanos (2006, p. 25) writes: “The university is the place par excellence where unconditional free speech and questioning shall be guaranteed and exercised.”

In the case of social researchers, when referring to freedom and contextualization, it ought to be borne in mind that there are different forms of power – formal and informal – which they must reckon with in order to be able to comply with their research work. Furthermore, the struggle in the scientific field described by Bourdieu (1984, p. 135) becomes more complex according to each context, for it leads to a conflict of interest among the protagonists, since both evaluators and subjects of assessment turn out to be colleagues and competitors; if this situation should become more complex still, the research field may become an “apparatus,” thus giving way to pathological situations (Bourdieu 1984, p. 158).

Bourdieu (1984, pp. 157–158) expresses the difference between research field and research apparatus by stating that the research field is the scenario of the struggle

between agents and institutions, with different forces, and in accordance with the constitutive rules of this space. And while those who exert power also have the means to do so, they are also resisted by the rest. On the other hand, when those who dominate the field possess the means to counteract resistance, the field becomes an “apparatus.”

It is, therefore, necessary to elucidate the power mechanisms derived from established knowledge, and delve into the institutional network of this research work, thus discovering the existence of the so-called institution science (Bourdieu 2008) which tends to establish, as a model of scientific activity, and became the routine practice in which more scientifically decisive operations may be carried out without reflection or critical control under the impeccable appearance of visible processes.

In this light, Carrizo (2003) suggests conducting a political analysis of institutional relations, i.e., of the distribution of power, which turns out to be important in order to unveil certain factors that constitute limitations to the outlooks and practices of researchers as well as of others with whom, and for whom, they work. And, even though the transmission of research results in the scientific field has been traditionally conducted by the researchers in the presence of their peers and/or their students and postgraduates, the twenty-first century calls for a further step in this line of work in order to secure the transference of those results to the field of public policy.

3 Transmission of Research Results in the Context of Public Policy

3.1 Public Policies

In a broader sense, public policies may be defined as the response governments give to arising problems. This leads us to evoke the historical existence of two opposite models which presuppose different ways of engaging in politics, i.e., public policy formulation and public policy implementation (Tonon 2010b). In that respect, Oszlak (1980, p. 4) sustains that, in their formulation, public policies are the genuine expression of public interest, and their legitimacy derives from a democratic legislative process or from the act of applying technically rational criteria and knowledge to the solution of social problems. However, implementation, which occurs in the bureaucratic context of the state, is related (in the popular imaginary) to routine, inefficiency, and corruption. Oszlak (1980, p. 11) goes on to say that the action of state institutions ought not to be merely regarded as the implementation of a set of norms but also as an attempt to achieve compatibility between their clientele's interests and their own, i.e., the interests upheld in their political projects by regimes that succeed one another in office.

In a previous research study, Oszlak and O'Donnell (1976, p. 21) had already defined public policies as “a set of actions-omissions which reveal a certain form of state intervention regarding an issue that may claim the attention, interest, or mobilization of other civil society actors.” They further made it plain that this process included successive simultaneous decisions emanated from several organisms of the state, thus ensuring that the position adopted would not necessarily be univocal, homogeneous, or permanent. Later on, Regonini (1989) identified five

analytical categories to explain the public policy formulation and implementation processes, namely, characteristics of the most influential and recurrent actors, style of decision-making processes, dynamics of the stages of the public policy's life cycle, structure of the policy problem, and the rules of the game. Thus, an analysis of public policy ought to consider, within a space-time dimension, the conditions of its emergence, the dynamics of its development, and the tendencies and contradictions of its political- institutional unfolding (Fleury 1997, p. 172).

Although traditional public policies have been designed in terms of the satisfaction of social or collective rights, as an external activity and provided by the state, a change of focus has recently been promoted. This shifts from the traditional one to a focus on human rights, characterized by an attempt to construct a reflective capacity oriented to the development of a type of citizenship not merely involved in political-state recognition but also in a sociocultural kind. In other words, the tendency is to promote a process of public policy formation characterized by stage interaction and the possibility of a permanent actor-decision adjustment with the object of enhancing results (INDES 2006).

3.2 The Relation Between Public Policies and Research Knowledge

Landri, Lamari, and Amara (2003, p. 194) explored the studies related to knowledge utilization and discovered that the pioneering studies in this field paid attention to variables related to the characteristics of the research products (see Caplan 1975; Weiss 1981). Another group of scholars were dedicated to the importance of policy contextual factors (Sabatier 1978; Webber 1984; Lester 1993). More recently, a group was devoted to the study of the importance of other explanatory factors, such as dissemination and links and exchanges between researchers and the use of research (Huberman 1994; Lomas 1997, 2000).

In 1979, Weiss published her emblematic article *The Many Meanings of Research Utilization* in which she expresses the following:

This is a time when more and more social scientists are becoming concerned about making their research useful for public policy-makers, and policy-makers are displaying spurts of well publicized concern about the usefulness of the social science research that government funds support. There is mutual interest in fathoming whether or not social science research aiming to influence policy is actually being used; but before that important issue can be properly addressed, it is essential to understand what using research actually means. (p. 426)

Weiss sums up the seven meanings she proposes for research utilization (pp. 427–430):

- Knowledge-driven model: it is the scheme that derives from natural science, composed of successive stages, basic research, applied research, development, and application.

- Problem-solving model: it implies the direct utilization of knowledge generated in the scientific field, with the aim of solving a pending problem in the social and political arena. Two cases may arise: (a) that the knowledge may already exist, in which case policy-makers will utilize it in order to make a decision, and (b) that the policy-makers may have a notion of what is needed and thus require that the researchers should work in that direction in order to generate the abovementioned knowledge.
- Interactive model: in this case, the policy-makers utilize information, not only produced by researchers but also by other social actors (citizens, planners, journalists, other politicians, administrators, groups of interest, NGOs, etc.).
- Political model: at times, a nucleus of interest regarding a certain political topic may bias the position of policy-makers, thus rendering them non-receptive to new knowledge generated in the research field.
- Tactical model: it is used by policy-makers in certain situations in which research is considered to be proof of their responsibility in the issue or when they wish to delay a decision, arguing that it is being developed in the research field, or to shirk their responsibilities in unpopular decisions.
- Enlightenment model: enlightenment is the most frequent way in which research may relate to decision-making.
- Research as part of the intellectual enterprise of the society: research utilization looks upon social science research as one of the intellectual pursuits of a society.

Weiss concludes that the time has come when importance must be given, not only to an increase in the utilization of research results applied to political decision-making but also to the increase and improvement of research contributions with political knowledge.

In that same year, the OECD Committee for Scientific and Technological Policy published the report *Social Science in Policy Making*, which also constituted an important document for the analysis of the relation between social sciences and the generation of public policies. James Mullin, coordinator of the abovementioned committee, made special emphasis on the fact that one of the major responsibilities of political decision-makers and researchers is the development of a mutual understanding of each other's tasks. This shows that, back then, there was a concern about progress and the most effective utilization of scientific knowledge for the resolution of social problems (Carrizo 2004).

In 1996, Davis and Howden-Chapman posed the question regarding the ways in which research work was reflected in public policies, and they arrived at the conclusion that "it was by some process of natural diffusion; or should it be conceived more actively as a matter of dissemination supplemented by a conscious program of implementation?" (p. 867).

The interaction between science and public policy, which was initially conceived through engineering models that presupposed a utilitarian or linear incorporation of scientific results to public policies, has nowadays become the object of interactive, reflective, or critical studies, which are not merely based on a practical utilization of knowledge (Estébanez 2004). At this point, we ought to identify the difference

between transference of research to policy and the term “knowledge transfer” which describes the activities conducted during the process of generating knowledge based on user needs, disseminating it, building capacity for its uptake by decision-makers, and finally tracking its application in specific contexts (Almeida and Báscolo 2006).

Several decades later, Crewe and Young (2002) carried out a review of the current literature on the subject and concluded that there are three major dimensions to consider regarding the impact of research on public policy:

- *Context: politics and institutions*, which includes the interests of key policy-makers and researchers, structures, and ideologies they were limited by; whether the policy changes were reformist or radical, how organizational pressures operated, and to what extent policies were adapted, developed, or distorted when put into practice.
- *Evidence: credibility and communication*, which implies investigating the impact of research findings and raising questions about the credibility of the research that has made some impact and the way in which it was communicated to policy-makers.
- *Links: influence and legitimacy* are important to find out the identity of the key actors, the roles they have played, the links between them, and the extent to which the research methodology has given legitimacy to the findings (Crewe and Young 2002, p. 5).

In 2004, Carrizo developed a research study in which he identified authors who pointed out the existence of different obstacles in the transformation of political culture – i.e., in the ranking of social research and its products as improvement factors in decision-making. Carrizo (2004, pp. 77–79) identified some of them. Tactic obstacles are derived from the possibility that the research might provide knowledge which may promote decisions considered to be outside the electoral acceptance zone. Temporary obstacles reveal how the offer of an answer to urgent issues is regarded as being menaced by scientific culture, since the latter requires longer processes and high academic standards. Communicational obstacles suggest that the characteristics of scientific discourse might discourage its usage by political actors. Epistemic-praxis obstacles point to the fact that the need to simplify increasingly complex realities in decision-making does not articulate easily with the complexity of social research. Historical-political obstacles suggest that in circumstances when political parties have a central role, they tend to hinder any relevant incorporation of technical and scientific logics in the process of decision-making. Philosophical obstacles tend to warn political actors against the risks of technocratic elitism which may not contribute to the construction of democracy.

Scientific and technological advice is a process which links at least two well-defined sectors: producers of scientific and technological knowledge acting as advisors and the state, as knowledge user in decision-making (Estébanez 2004). This link may derive from advisory boards composed of scientists acting in governmental institutions; consulting processes with scientists, on the face of a crisis or

problem; legislative science and technology advisors; and the presence of scientists in technical functions or government policies (Estébanez 2004).

According to the traditional view, scientific knowledge is regarded as an *accumulable product* which decision-makers can resort to according to their needs. This conception is generally allied with a simplified view of the decision-making process (Pellegrini 2000), under the assumption that policy formulation and implementation are a linear process comprising a chain of rational decisions made by privileged actors. In this respect, the problem seems to lie in making the right information available to decision-makers, at the right moment (Almeida and Báscolo 2006).

Evidence can occupy an important place in the policy-making process if it is available when needed, if it is communicated in terms that fit with policy direction, and if it points to practical action (Nutbeam and Boxall 2008). Orton et al. (2011) identified in their study of barriers that hinder the use of research evidence, decision-makers' perceptions of research evidence, the gulf between researchers and decision-makers, the culture in which decision-makers operate, competing influences on decision-making, and practical constraints.

Bowen and Zwi (2005, p. 600) propose an "evidence-informed policy and practice pathway to help researchers and policy actors navigate the use of evidence." The pathway involves three active stages of progression, influenced by the policy context: sourcing, using, and implementing the evidence. It also involves decision-making factors and a process they call *adopt, adapt, and act*. At the same time, Orton et al. (2011) also suggested ways of overcoming these barriers by proposing that research should meet the needs of decision-makers, research clearly highlighting key messages and capacity building.

Nielson (2001) summarized the different theories to explain the under-/non-utilization of knowledge or research by policy-makers for decision-making purposes. Caplan (1979) proposes his theory of the "two communities," arguing that the limited use of research by policy-makers is, in part, due to the fact that researchers and policy-makers have different worldviews. Later explanations based on the writings of Weiss (1977), Webber (1991), Sabatier and Jenkins-Smith (1993), and others include the idea that the research-policy link is not a direct one, particularly regarding data and information sources. These writings support the position that research is only one of many sources of information for policy-makers and that it is not a simple dichotomy between "use" and "non-use" but rather that knowledge/research utilization is built on a gradual shift in conceptual thinking over time. This represents what Weiss coined as the "enlightenment function" of research.

3.3 Relationship Between Researchers and Policy-Makers

Regarding the relationship between researchers and policy-makers, Crewe and Young (2002, p. 14) stated that when both have close personal links, with appropriate chains of legitimacy to those whom they represent, researchers should have a higher influence, and policy-makers could make better use of research. Crewe and Young (2002, p. v) suggest that "policy makers and researchers cut across categories

but their position of power and the aims of the organizations they work for, can be identified.”

Policy decision-makers as well as researchers and academics need to see eye to eye and take into consideration the social macro- and micro-dimensions in their daily tasks (Tonon 2015). Thus, Torres Carrillo (2006, p. 94) comes to mind when he points out that subjectivity crisscrosses social life and is present in all the social dynamics of daily life, both in micro-social and macro-social spaces and in daily intersubjective experience and in the institutional structure of the time.

Interrelations between researchers and decision-makers have been considered a prime factor in analyzing knowledge transfer processes. Analysis of the models of interrelations between researchers and decision-makers is relevant when one realizes that the use of scientific knowledge depends largely on certain characteristics of the actors, that is to say, the researchers’ behavior and the decision-makers’ receptiveness (Almeida and Báscolo 2006).

At this point, it is vital to reflect upon the characteristics of both researchers and policy-makers. Social researchers are individuals who related to other individuals; thus the products generated by those research processes are both socially and historically constructed (Tonon 2015). From the point of view of the social researcher, “his objects are not only objects for his observation but also beings that possess their own pre-interpreted world and carry out their own observation; they are fellow creatures inserted in a social reality” (Natanson 1974, p. 23). Brown (1991) argues that quantitative and qualitative databases and statistical indicators cannot be considered research results per se but are the raw material on which research is shaped and without which it cannot be conducted. He also emphasizes that “documentation is not always a step towards action; sometimes it stultifies it” (p. 28).

In the case of policy decision-makers, they require quantitative and qualitative indicators to obtain the information they supply – if they are to generate public policies that not only cater for the subjects’ external living conditions but also to their quality of life in multidimensional terms (Tonon 2015). In this matter, we coincide with Veenhoven (2000) who expressed that public policies are not merely limited to material issues but are also extensive to affairs related to people’s mentality.

There is a considerable difference between what scientists and policy-makers consider as knowledge, as well as the difference between how that knowledge has been developed or obtained. Social scientists generally regard knowledge as something that is theoretically and methodologically sound and/or defensible. Policy-makers see knowledge as the result of experience (Nielson 2001, p. 6).

Research quality often determines the credibility of the organization that either conducts or financially supports the research and, as such, may also determine the credibility and/or integrity of the research field itself as a source of useable knowledge. In relation to the concept of research quality, Seck and Phillips (2001) regard rigor as a primary quality or characteristic which may help to determine the quality of the research – a rigorous research being the one that is free of fault in design, method, and interpretation. They further point out that it is not synonymous with academic or path-breaking theoretical research. The authors also explain that another important characteristic is completeness, which is a concept related to the exploration of all potential

options, as well as making available all relevant facts and figures that research can uncover in the search for intrinsically good policy options (Seck and Phillips 2001, p. 4).

Nielson (2001, p. 11, quoting Weiss 1991) recognizes three models of “research” used by policy-makers: research as data, research as ideas, and research as argumentation. The first model is more mechanistic in terms of its application to the problem at hand. It assumes that the data or sets of findings obtained meet the users’ needs and that there is no conflict in terms of what solution, or goal, is desired or required in order to resolve the problem. The second one is perceived to be more general in nature, applied to situations in which problems are regarded as complex in nature, i.e., when uncertainty is high and ideas are in demand. Finally, research as argumentation is used when a decision has already been made and policy-makers and/or interest groups draw on research to take an advocacy position.

Reimers and McGinn (1997, p. 22) propose four types of research. First is academic research which is the research where systems of explanation are composed by theories, models, and conceptual frameworks. Second, planning research is a kind of research that uses statistical analysis to generate patterns of relationships among variables. Third is instrumentation research where repeated trial and error methods are used in the instrumentation process of preparing a new curriculum. Fourth is action research which has its focus on the outcomes themselves rather than in the knowledge of how to achieve them.

Uzochukwu et al. (2016) point out that the failure of the utilization of high-quality research evidence by decision-makers has been singled out as the gap between research and policy. The authors quote Lomas (1997), identifying four misunderstandings between the evidence production and the policy-making effort. The first point is that researchers and policy-makers consider each other’s activity as the act of generating products rather than engaging in processes. Secondly, scientific research attempts to focus on the question, so that a clear and crisp answer may be provided, whereas policy-making considers other variables such as interests, ideology, values, or opinions. Thirdly, decision-makers are not sensitive to the incentives that drive researchers, such as attracting grant money and publishing in peer-reviewed journals, causing them to be reluctant to respond to issues that are politically current for government policy-makers. In the fourth place, researchers rarely take into account their potential research audiences (Lomas 1997).

Various authors have examined and promoted different ways of improving interrelations between researchers and decision-makers, such as collaborative or “allied research” (Pittman 2004), constructivist approaches or evaluative research (Furtado 2001), including strategies to improve the knowledge output for decision-making.

Campbell et al. (2009) developed a study which expresses that better communication is often suggested as fundamental to increasing the use of research evidence in policy, but little is known about how researchers and policy-makers work together or about the barriers they are faced with. This study has explored the views and practice of policy-makers and researchers regarding the use of evidence in public policy, including current use of research evidence to inform policy,

dissemination of and access to research findings for policy, communication and exchange between researchers and policy-makers, and incentives for an increase in the use of research in policy-making (Campbell et al. 2009, p. 1). The results of the study show that policy-makers and researchers acknowledge the potential of research as a contribution to policy and are making significant attempts to integrate research into the policy-making process, although only half of the researchers believe their research to have been used to get issues on the policy agenda, or to select preferred policy options, in the past 2 years. These findings suggest four strategies to assist in increasing the use of research in policy-making: making research findings more accessible to policy-makers; increasing opportunities for interaction between policy-makers and researchers; addressing structural barriers, such as research receptivity in policy agencies and a lack of incentives to lure academics to link with policy; and highlighting the relevance of research to policy-making (Campbell et al. 2009, p. 1).

4 Conclusions and Future Directions

I propose reconsidering social science research in the light of the challenges of the twenty-first century. González Perdomo (2006, p. 28) suggests that “social research must be conceived as a kind of experience with life, in which, through an exhortation to dare to think, such experience can become significant and transforming.” About the use of knowledge, Nielson (2001, p. 7) quotes Webber (1991, pp. 5–6) who states that use is understood to mean consideration, while the exact process of use has been given different interpretations – and little effort has been made to compare approaches to measuring knowledge use in the same sample of policy-makers.

It ought to be borne in mind that scientific arguments are important in some areas of policy-making and that policy-makers could make more constructive use of research, while researchers could communicate their findings more effectively in order to influence policy-making. Crewe and Young (2002, p. 1) contend that “if more were understood about the context within which researchers, policy makers, and stakeholders are working, the links between them would be enhanced, and good quality research would be disseminated more effectively, thus, better policy making might ensue.”

In order to increase the relevance of research, policy-makers need be able to clearly identify and acquaint researchers with gaps in knowledge and policy priorities that require research. A greater understanding of the policy context by researchers could increase relevance by focusing the research on more useful questions, collecting information instrumental to policy decisions, and improving the description of the research results and their implications (Campbell et al. 2009). With the right level of interaction between researchers and decision-makers, the translation of research findings into actionable policy and programmatic guidance is an achievable goal (Uzochukwu et al. 2016).

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Appraisal of Qualitative Studies

58

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Contents

1	Introduction	1014
2	Debates and Challenges of Appraising Qualitative Research	1015
3	Conceptualizing Rigor in Qualitative Research	1016
4	Techniques to Enhance Rigor	1017
4.1	Participant Selection and Recruitment	1018
4.2	Data Collection	1018
4.3	Data Analysis	1019
4.4	Interpretations and Conclusions	1020
5	Guidelines for Appraising Qualitative Research	1021
6	Proposed Strategy for the Appraisal of Qualitative Health Research	1024
7	Conclusion and Future Directions	1025
	References	1025

Abstract

The appraisal of health research is an essential skill required of readers in order to determine the extent to which the findings may inform evidence-based policy and practice. The appraisal of qualitative research remains highly contentious, and there is a lack of consensus regarding a standard approach to appraising qualitative studies. Different guides and tools are available for the critical appraisal of qualitative research. While these guides propose different criteria for assessment,

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1013

overarching principles of rigor have been widely adopted, and these include credibility, dependability, confirmability, transferability, and reflexivity. This chapter will discuss the importance of appraising qualitative research, the principles and techniques for establishing rigor, and future directions regarding the use of guidelines to appraise qualitative research.

Keywords

Appraisal · Quality criteria · Qualitative research · Rigor · Trustworthiness

1 Introduction

Qualitative research, like all research, must be read and judged with a critical eye before accepting their findings as trustworthy and relevant to practice. Critical appraisal is, therefore, an essential process in the translation of research into health policy and practice (Hill and Spittlehouse 2003). Significant responsibility falls onto the researchers, who must report their methods in sufficient detail and highlight the limitations that may impact the validity and relevance of their findings (Patton 1999). Health research has a broad audience, including stakeholders with limited expertise in research methods. Standard checklists and tools for evaluating different types of quantitative studies have been widely adopted in order to equip readers with the skills to systematically examine research evidence, for example, the Cochrane collaborations' risk of bias tool for clinical trials (Higgins et al. 2011). Various approaches have been developed to appraise qualitative research, but there is little agreement among researchers as to standard criteria or a gold-standard approach to conducting qualitative research. The diverse approaches used in qualitative studies, for example, phenomenology, ethnography, and grounded theory, are founded on varying theoretical frameworks and philosophical assumptions about the nature of reality and knowledge (Patton 2015). It is unlikely that one standard set of criteria for qualitative research will be developed that will be applicable to the whole range of qualitative approaches (Barbour 2001).

There has been greater demand and interest in qualitative research in health and also notably in medicine. This may reflect the paradigm shift toward patient-centered care, which requires an understanding of the values, goals, beliefs, and attitudes of patients. The British Medical Journal and the Medical Journal of Australia have published educational articles providing criteria for the appraisal of qualitative research (Kitto et al. 2008; Kuper et al. 2008; Mays and Pope 2000). However, the audiences of biomedical journals are largely trained in a positivist tradition of science, which seeks to uncover an objective reality through scientific methods (Meyrick 2006). Qualitative research is interpretive and naturalistic, using distinct methods to explain and describe a phenomenon (Liamputtong 2013; Patton 2015). Readers who are unfamiliar with qualitative research are typically focused on aspects of rigor that are associated with the quantitative methods (Meyrick 2006). Qualitative research is frequently judged by inappropriate standards and criteria (Tong and Dew 2016). With uncertainty as to how to interpret and assess the findings of qualitative studies, it is no surprise that their methods are viewed with some skepticism and even as "second class" by funding agencies, clinicians, and policy

makers (Tong et al. 2007). The appraisal of qualitative studies is, therefore, particularly important for qualitative research to be accepted and recognized for its strengths and their findings to produce detailed and nuanced evidence that can inform ways to improve health (Patton 2015). Many of the tools that are currently available require considerable understanding and experience in qualitative research methods and principles (Mays and Pope 2007).

This chapter will discuss the importance of the critical appraisal of qualitative health research, with particular focus on the principles of rigor including credibility, dependability, confirmability, transferability, and reflexivity. Specifically, this chapter will address the debates and challenges that surround the appraisal of qualitative research, discuss techniques to enhance rigor, outline examples of available guidelines for the appraisal of qualitative research, and discuss future directions in the appraisal of qualitative research.

2 Debates and Challenges of Appraising Qualitative Research

There is much contention about appraising qualitative research, which will be briefly summarized in this section. The extreme relativist perspective argues against the use of criteria to judge quality, rejecting the existence of a single truth independent of the researcher and study context (Mays and Pope 2000; Meyrick 2006). Among those who support the appraisal of qualitative research, there is debate as to how quality should be judged. Anti-realists argue that the distinct qualitative research paradigm requires a set of criteria to assess quality that is unique from the quantitative criteria (i.e., validity and reliability) (Mays and Pope 2000; Meyrick 2006). This approach emphasizes that multiple accounts can be produced of a phenomenon because of the influence of the researcher and the methods on the knowledge generated (Dixon-Woods et al. 2004). Others believe that the principles of validity, reliability, and objectivity can be broadly applied to qualitative research, with some adjustment in the criteria to take into account the unique goals and methods of qualitative research (Mays and Pope 2000; Noyes et al. 2008). This is based on the subtle realist argument that an underlying reality, rather than single truth, can be obtained from qualitative research (Mays and Pope 2000). Core concepts of rigor have been developed specifically for qualitative research, with some overlap with the concepts used in the quantitative research paradigm. These are discussed in the following section.

The appraisal of qualitative research is not straightforward and requires an understanding of diverse qualitative principles, methodologies, and methods. Readers are required to judge whether the study design is appropriate to the research question and whether the methods were rigorous such that the findings can be trusted (Giacomini et al. 2000). Unlike quantitative research, the appraisal of qualitative research cannot be reduced to black and white questions, for example, is the sample size sufficient for statistical power? (see ► Chap. 59, “Critical Appraisal of Quantitative Research”). Rather, the appraisal requires the reader to make a judgment regarding the appropriateness of the methods and the adequacy of the sample, data collection, and analysis (O’reilly and Parker 2013). Similarly, there is no agreement regarding the gold-

standard approach to conducting qualitative research (O'reilly and Parker 2013). For example, interviews are not considered superior to focus groups or field observation. The appropriateness of the methods depends on the research question and the methodological framework guiding the study. The appraisal process is, therefore, necessarily interpretive and can be quite challenging for researchers who are unfamiliar with the qualitative research paradigm and principles of rigor.

3 Conceptualizing Rigor in Qualitative Research

The traditional criteria for rigor in the quantitative paradigm are well known. These include trustworthiness (internal validity), generalizability (external validity), consistency (reliability), and objectivity (Mays and Pope 2007). Different terminology and criteria for rigor have been proposed for qualitative research, which have used these same core principles (Mays and Pope 2007). Lincoln and Guba (1986) have proposed four constructs to appraise rigor in qualitative research that align with these principles from the conventional paradigm: credibility, dependability, transferability, and confirmability (see Table 1).

Credibility aligns with the principle of internal validity and addresses whether the findings and judgments made by the researchers can be trusted and the extent to which they provide comprehensive and sensible interpretations of the data (Lincoln and Guba 1986). The question guide used in interviews or focus groups could be examined to determine whether the questions that were asked were appropriate and enabled participants the opportunity to provide in-depth responses relevant to the research question. Authors should provide thick description, which means to describe the data in detail and provide contextual information (Liamputtong 2013). Member checking, which involves obtaining feedback from the participants on the preliminary analysis to ensure that it reflects their perspectives, and investigator triangulation can ensure that the interpretations capture the range and depth of the data that was generated (Liamputtong 2013).

Confirmability parallels the principle of objectivity, such that the authors attempt to demonstrate that the findings and interpretations are linked to the data, and reflects the perspectives of participants (Lincoln and Guba 1986). This can convince the audience that the results and conclusions are not unduly influenced by the biases, assumptions, and experiences of the researcher. Qualitative research is inherently interpretive, but involving multiple investigators, providing quotations that support the findings, and

Table 1 Criteria for rigor in qualitative and quantitative research (Lincoln and Guba 1986; Kitto et al. 2008)

Common principle	Qualitative terminology	Quantitative terminology
Truth/reality	Credibility	Internal validity
Applicability/relevance	Transferability	Generalizability or external validity
Consistency	Dependability	Reliability
Neutrality	Confirmability	Objectivity

having participants check the interpretations can ensure that the findings reflect the full depth and scope of the participants' experiences and perspectives.

Dependability is similar to the criteria of reliability (Lincoln and Guba 1986). While it is not feasible to reproduce a qualitative study, the research process should be logical and transparent, such that the process and procedures can be auditable and traced. The research process and analytical decisions should be recorded (Liamputtong 2013). There should be coherence across the methods and findings. These aspects can be demonstrated by recording and transcribing the data and using software to facilitate coding and to store, manage, and retrieve data.

Generalizability, or external validity, is not directly applicable to qualitative research. Qualitative studies often include a small number of participants who can provide rich information on a topic. The criteria of transferability, which refer to the relevance and potential applicability of findings to other settings and contexts, are applied in qualitative research (Lincoln and Guba 1986). The reader looks for resonance between the study setting and sample and their own context (Kuper et al. 2008) and makes a judgment about whether the findings are relevant to them. This requires researchers to report their study with sufficient detail so that the reader understands the context of the study and the findings. Transferability can also be demonstrated by comparing the results with other health-care contexts and populations or existing theoretical models.

Some additional criteria for rigor have been proposed. Theoretical or conceptual rigor establishes that the research design is appropriate to the research question and the aims of the study (Liamputtong 2013). This requires a clear research question that is articulated in the aims of the study (Kitto et al. 2008). The theoretical approach and methods should be clearly justified in terms of the relevance to the research question (Kitto et al. 2008). Many published qualitative studies do not specify the study design or theoretical perspective that has been used (Dixon-Woods et al. 2004). Of note, some studies may purport to use a specific methodological approach, e.g., phenomenology or grounded theory, but the process by which this was applied may not be aligned with the stated methodology (Barbour 2001). Interpretive rigor assesses the extent to which the researchers produce accurate, trustworthy interpretations of the findings, which are relevant to the intended audience, and produce a depth and breadth of understanding of the phenomenon (Liamputtong 2013). This covers credibility, confirmability, and transferability but also considers the impact of the interpretations that are produced. Some studies may have been rigorously conducted and reported yet provide little insight into the phenomenon being studied (Noyes et al. 2008).

4 Techniques to Enhance Rigor

A number of techniques can be used to enhance the confirmability, transferability, dependability, and credibility of qualitative research (Liamputtong 2013). However, the use of a single technique does not guarantee that a qualitative study is rigorous. In the following section, we have outlined different strategies for improving rigor, focusing on

the different components of study design and process including participant selection and recruitment, data collection, data analysis, and the interpretations and conclusions.

4.1 Participant Selection and Recruitment

The appropriateness of the sample should be assessed in reference to the aims of the research study (Kuper et al. 2008). There are a range of strategies for selecting participants. Qualitative research generally seeks to include a broad range of information-rich participants to capture wide variation in the phenomenon and perspectives, and this can be achieved using purposive sampling (Sandelowski 1995; Patton 2015). Snowballing sampling strategy involves asking initial participants to identify other people how may fit the inclusion criteria and be willing to participate in the study. Snowballing is suitable for identifying participants from hidden populations who are difficult to approach directly, for example, drug users (Liamputtong 2007, 2013). Convenience sampling is not recommended for qualitative research as this is likely to lead to a homogenous sample with a single experience or perspective, rather than capturing a range of experiences (Liamputtong 2013). Nevertheless, it is commonly used as it is an efficient, cheap, and easy strategy to select participants. The potential biases and limitations of the sample should be discussed by the researchers.

The selection criteria may change during the analysis process, but the rationale for including participants should be clearly justified (Giacomini et al. 2000). Limitations in the sampling should be discussed, particularly regarding the absence of participants with important characteristics (Kuper et al. 2008; Patton 2015). Qualitative studies will usually not have a predetermined sample size, as the sampling is ceased when a thorough understanding of the phenomenon has been achieved and participants are no longer raising new insights (i.e., data saturation) (Kuper et al. 2008; Liamputtong 2013). Many researches do not justify their decision to stop recruitment (Giacomini et al. 2000). In reality, recruitment may need to cease due to resource constraints and feasibility before saturation has been reached (O'reilly and Parker 2013). This should be discussed in the paper. Alternatively, saturation is often cited, but it is unclear to readers how this was achieved, perhaps stemming from a lack of guidance and clarity among researchers the process of achieving saturation (O'reilly and Parker 2013). A recent study that interviewed first-time fathers' postnatal experiences and support needs in the early postpartum period reported that they reached after the 13th participant and conducted two additional interviews to confirm that they were not identifying new findings (Shorey et al. 2017). The reader should also examine the characteristics of the sample and the breadth and depth of the results to make a judgment as to whether the sample included varying cases and participants.

4.2 Data Collection

Readers should question whether the data were collected appropriately based on the research question (Kuper et al. 2008). For example, the selection of interviews, focus

groups, or field observation as the method for collecting data will ultimately depend upon the aims of the study. The choice of methods should be clearly justified in the research report.

Field observation should consider whether the presence of a researcher may influence the behavior of participants rather than observing events as they naturally occur (Giacomini et al. 2000). Individual interviews are suitable for eliciting personal experiences and perspectives, particularly regarding personal and emotional topics. Focus groups are useful for generating data that capitalizes on group interactions and dynamics (Krueger 2014). While the group dynamic in focus groups may empower participants to speak about emotionally sensitive experiences among people with similar experiences, the inappropriate composition of the group can inhibit disclosure (Liamputtong 2011). For example, a focus group study is more suitable than interviews to study the barriers to medication adherence among young people living with HIV, as the rapport among participants may facilitate more open communication regarding this sensitive and stigmatized issue (Rao et al. 2007). Interview and focus group studies should minimize power imbalance between the researcher and participants, for example, where possible, patients should not be interviewed by a clinician involved in their care (Råheim et al. 2016). This should be mentioned in the report.

Triangulation using multiple methods for collecting data can help produce more comprehensive findings and compensate for any disadvantages associated with one particular method (Patton 2015). Different methods can be used to look for patterns of convergence or to help build the interpretations of the phenomenon. Triangulation commonly produces findings that are at odds with each other, due to producing different types of information under different settings (Patton 2015). Inconsistencies provide an opportunity to further understand the phenomenon and the relationship between data collection methods and the findings (Patton 2015). These issues should be explored in the research report.

It should also be demonstrated to readers that the data collection was systematic, organized, and comprehensive enough to produce robust and in-depth descriptions of the phenomenon (Giacomini et al. 2000; Kuper et al. 2008). This cannot be judged by the sample size alone, as a large sample may not extensively study each individual participant and produce findings that are shallower and less nuanced than a study of smaller sample with more in-depth analysis of the interactions with participants (Giacomini et al. 2000). In addition to sample size, readers should look at other indicators including the number of observations or interviews, duration of the data collection, diversity of data collection and data collection techniques, and the number of investigators involved in collecting the data (Giacomini et al. 2000).

4.3 Data Analysis

There are many different frameworks for qualitative analysis, thus the approach chosen should be justified and appropriate to the objectives of the study (Kuper et al. 2008). Unlike statistical analysis which follows formulas and rules and can be

performed using statistical analysis software, qualitative researchers are the “instrument” in the analysis, as their interpretations and expertise are required to analyze the data (Patton 2015). It is, therefore, critical that qualitative analysis is performed systematically and clearly described (Patton 2015). Qualitative data collection and analysis therefore also require training and guidance by an experienced researcher (Patton 2015). Important skills that require practice and experience include asking questions, prompting for further information, building rapport with participants, recording detailed field notes, and distinguishing important and relevant data in the analysis (Patton 2015). Software can be used to perform the analysis systematically; however, it does not automatically ensure that a high-quality analysis is achieved (Giacomini et al. 2000).

The goal of qualitative analysis is to develop a conceptual framework that provides in-depth and broad understanding of the phenomenon. Researcher triangulation and respondent validation can also be associated with improved rigor of the analysis. Involving multiple investigators allow for discussion to further develop the analytical framework, ensuring all the data is captured and preventing the biases of a single researcher from unduly influencing the interpretations (Giacomini et al. 2000; Kitto et al. 2008). Respondent validation (or member checking) involves seeking feedback on the interpretations from the participants, ensuring it is meaningful to those who participated (Giacomini et al. 2000; Liamputtong 2013). This has been suggested to be the strongest marker of credibility of the analysis (Lincoln and Guba 1986). Their feedback generates new data that requires further analysis (Mays and Pope 2007). Researchers should also test for alternative explanations and consider negative cases that do not fit with their preliminary conceptualizations of the data, to refine and develop the analysis (Mays and Pope 2000; Patton 2015). Fair dealing is another technique to ensure that the perspectives of the participants are represented fairly. The analysis should capture a range of perspectives and avoid presenting the viewpoint of one group as the majority opinion or experience (Mays and Pope 2000).

4.4 Interpretations and Conclusions

The interpretive rigor of a study should be assessed in terms of whether accurate, trustworthy, relevant, and in-depth understanding of the phenomenon is presented (Liamputtong 2013). Given the direct involvement of the qualitative researcher in analyzing and interpreting the findings, a criterion for rigor in qualitative research involves the demonstration of reflective thought (i.e., reflexivity) to minimize researcher bias and ensure the findings capture participant’s perspectives (Giacomini et al. 2000; Kuper et al. 2008; Liamputtong 2013). Reflexivity requires the researcher to acknowledge and address the influence they may have on the data collection and study results and assess the potential sociocultural, political, or ethical influences on the research (Liamputtong 2013). The researcher’s background, gender, and professional role may influence their design of the study and shape the data that is collected from their interactions with participants and their interpretations of the data (Kuper et al. 2008; Patton 2015). For example, there may be a power

imbalance between the researcher and the participants, an inclination to perform in the presence of an observer or provide desirable responses (Anyan 2013). The researcher's own attitudes and biases may change during data collection (Patton 2015). These changes should be systematically recorded and assessed in the research report. Readers should have sufficient information to make an assessment regarding the likely influence of the researcher on the study.

A number of techniques have been described in this section, which can be used to demonstrate the credibility, transferability, dependability, and confirmability of a qualitative study (see Fig. 1). Importantly, these techniques require detailed description, reporting, and justification to enable readers to make an assessment of the rigor of the study methods and interpretations (see also ► Chap. 55, "Reporting of Qualitative Health Research").

5 Guidelines for Appraising Qualitative Research

There is a lack of consensus among experts about the most appropriate criteria for assessing qualitative research and by what indicators these criteria should be assessed (Dixon-Woods et al. 2004). There have been over 100 proposed guidelines for assessing the conduct of qualitative studies, most of which are general criteria that can be applied across various qualitative methods (Dixon-Woods et al. 2004). The criteria used varies considerably across these frameworks; however most do address credibility to some degree (Noyes et al. 2008). Some argue that these criteria should be utilized as guides rather than rigid criteria presented as standard requirements for quality research (Kenwood and Pigeon 1992).

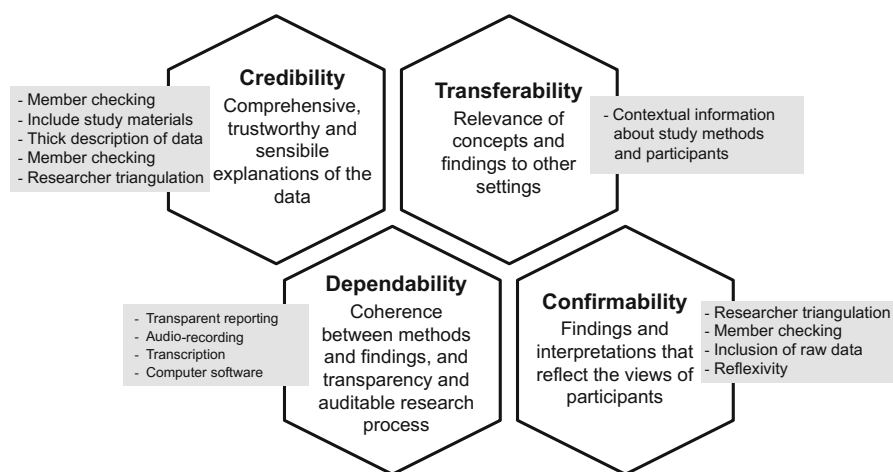


Fig. 1 Techniques to enhance the credibility, dependability, confirmability, and transferability of a study

Some guidelines provide a more structured procedure for evaluating rigor. Guidelines such as the Critical Appraisal Skills Programme (CASP 2017) and Spencer and colleagues' framework (Spencer et al. 2003) are widely used. However, neither of these tools proposes to be a strict set of standards or rules for qualitative research but rather provides an aid to inform judgments about the quality of a qualitative study. The CASP tool has been widely used in the synthesis of qualitative studies, to inform decisions about the exclusion of studies from a review (see ► Chap. 45, "Meta-synthesis of Qualitative Research"). It is a checklist consisting of ten questions that broadly cover methodological rigor, credibility, and relevance. Each item provides suggestions to consider when making an assessment. Despite offering a relatively structured process, agreement between researchers is not necessarily strong as the questions require subjective judgments (Dixon-Woods et al. 2007). An example of an appraisal item taken from CASP is shown in Table 2.

Spencer and colleague's framework (Spencer et al. 2003) has been described as one of the most comprehensive frameworks available (Pope and Mays 2006). The framework is underpinned by four central principles: contribution in advancing knowledge, the defensibility of the design, rigorous conduct, and credibility of the claims of the study. These principles were used to identify 18 questions that cover the study findings, design, sample, data collection, analysis, reporting, reflexivity, neutrality, ethics, and auditability. An advantage of this framework is the inclusion of comprehensive indicators to guide the readers in answering each question. This framework is also more general than other tools, including considerations for various types of data (e.g., document analysis) and methods (e.g., field observation). An example of the appraisal items related to sampling taken from this framework is shown in Table 3.

Kitto and colleagues (2008) developed criteria for authors and assessors of research articles submitted to the Medical Journal of Australia. These criteria cover domains including clarification and justification of the aims and methods, procedural rigor, representativeness of the sample, interpretive rigor, reflexivity and evaluative rigor, and transferability. Some of the items are straightforward as they are related to the reporting of aspects of the study design.

Many qualitative researchers have proposed general questions to guide the appraisal of qualitative studies (Popay et al. 1998; Mays and Pope 2000; Kuper

Table 2 CASP appraisal criteria related to the sampling (CASP 2017)

Item			Considerations
Was the recruitment strategy appropriate to the aims of the research?			If the researcher has explained how the participants were selected
<input type="checkbox"/> Yes	<input type="checkbox"/> Can't tell	<input type="checkbox"/> No	If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
			If there are any discussions around recruitment (e.g., why some people chose not to take part)

Table 3 Spencer and colleague's appraisal criteria related to sampling (Spencer et al. 2003)

Appraisal questions	Quality indicators to consider
How well defended is the sample design/target selection of cases/documents?	Discussion of study locations/areas and how and why they were chosen
	Description of population of interest and how sample selection related to it (e.g., typical, extreme case, diverse constituencies, etc.)
	Rationale for basis of selection of target sample/settings/documents (e.g., characteristics/features of target sample/settings/documents, basis for inclusions and exclusions, discussion of sample size/number of cases/setting selected, etc.)
	Discussion of how sample/selections allowed required comparisons to be made
Sample composition/case inclusion – how well is the eventual coverage described?	Detailed profile of achieved sample/case coverage
	Maximum inclusion (e.g., language matching or translation, specialized recruitment, organized transport for group attendance)
	Discussion of any missing coverage in achieved samples/cases and implications for study evidence (e.g., through comparison of target and achieved samples, comparison with population, etc.)
	Documentation of reasons for nonparticipation among sample approached/noninclusion of selected cases/documents
	Discussion of access and methods of approach and how these might have affected participation/coverage

et al. 2008). Dixon-Woods et al. (2004) provide a small number of generic prompts to guide the appraisal of qualitative research, which they emphasize are not pre-scriptive criteria. These include items relating to both the conduct and reporting of the study (see Table 4). They intend for these prompts to be supplemented by items specific to different methods and theoretical frameworks.

Across all these guides for the appraisal of qualitative research, a large component of this process of assessing study conduct relies largely on subjective assessments. This is particularly evident in items related to judgments of the appropriateness of the study methods, the adequacy of the sample size, and the quality of the insights and interpretations produced. This can be particularly challenging for researchers who have limited experience in a range of qualitative methods and principles. Available tools typically focus on the technical aspects of a study (i.e., methodological rigor). Some have also recommended that an appraisal of theoretical rigor be conducted (Noyes et al. 2008). This would involve an assessment of the congruence between the theoretical framework, methodology, and methods chosen.

There are also guidelines available for the appraisal of the transparency of reporting of qualitative studies (Tong et al. 2007), which can inform judgments about the overall study conduct. Systematic reviews synthesizing the findings from

Table 4 Adapted from Dixon-Woods prompts for the appraisal of qualitative research (Dixon-Woods et al. 2004)

Topics	Items
Research question	Are the research questions clear?
	Are the research questions suited to qualitative inquiry?
Methods	Are the following clearly described? (sampling, data collection, analysis)
	Are the following appropriate to the research question? (sampling, data collection, analysis)
Claims	Are the claims made supported by sufficient evidence?
Overall	Are the data, interpretations, and conclusions clearly integrated?
	Does the paper make a useful contribution?

qualitative research frequently show that aspects of the study are infrequently reported (Tong et al. 2007; see also ► Chap. 55, “Reporting of Qualitative Health Research”).

6 Proposed Strategy for the Appraisal of Qualitative Health Research

Given the vast differences in the appraisal guidelines that are available, and their generic nature, researchers should not rely on a single guideline or tool to appraise qualitative studies (Pope and Mays 2006). It is recommended that researchers read about rigor in the context of the relevant methods and methodological approach. For less experienced qualitative researchers, we suggest using guidelines that provide sufficient guidance regarding indicators to examine the criteria, for example, the CASP tool. It is recommended that the appraisal process is completed with the guidance of supervisor with experience in qualitative research methods and appraisal. Additional criteria could be added to available tools to ensure that components are assessed that are relevant to the methods of the chosen study (Dixon-Woods et al. 2004).

Some qualitative researchers have argued that the proliferation of standard criteria for quality in qualitative research has had a negative impact on study conduct and reporting. In particular, they attribute the prominent use of techniques such as “saturation,” “purposive sampling,” “respondent validation,” and “researcher triangulation” to the attempts of researchers to conform to perceived “standards” of qualitative research, without actually achieving or explaining these processes in their study (Barbour 2001; Dixon-Woods et al. 2004; O’reilly and Parker 2013). For example, Barbour (2001) suggests that grounded theory methodology is frequently used as “an approving bumper sticker,” while the data collection, analysis, and interpretations do not adhere to the assumptions and traditions that underpin this methodological approach. These issues are also symptomatic of the general problem with the limited transparency in the reporting of qualitative research methods, particularly the interpretive process.

Future work is needed to develop appraisal criteria that are specific to different methods and theoretical approaches in qualitative research (Dixon-Woods et al. 2004). This may help develop agreement on the “fatal flaws” in terms of limitations of a study that are critical or render one study better quality than another (Dixon-Woods et al. 2004; Noyes et al. 2008). This is particularly challenging in the context of appraising qualitative studies for inclusion in a systematic review. Currently, there is little guidance to assist with these decisions. The approach to appraising rigor using overarching principles rather than relying on the use of specific techniques, like the use of software, is therefore widely encouraged. It is therefore important for those appraising qualitative research to have a thorough understanding of the principles of rigor, in addition to using a guide or tool to assess quality in qualitative research.

7 Conclusion and Future Directions

The critical appraisal of qualitative research is essential to identify limitations in qualitative evidence and prevent readers from inappropriately transferring and applying their findings to decision-making, health care, and policy. Transparency in the reporting of qualitative research aims and methods is fundamental to enable readers to appraise various aspects of a qualitative study including the appropriateness of the methods and interpretations. Lincoln and Guba’s principles of credibility, transferability, dependability, and confirmability are useful for conceptualizing rigor across qualitative research. Various techniques can be used to achieve these principles of rigor including saturation, member checking, triangulation, and the use of software, depending on the methodological approach and research question. It is unlikely that a standard set of criteria will ever be developed that is indicative of quality across all types of qualitative research. As we have discussed above, further work is needed to develop additional criteria that are specific to different methods and theoretical frameworks in qualitative research. There is a need to improve understanding of the core principles of rigor and to encourage the use of appraisal tools to assist with the critical appraisal of qualitative research. Increased understanding and skills in the critical appraisal of qualitative research are required to ensure the acceptance of qualitative studies and to ensure their impact on health care.

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Critical Appraisal of Quantitative Research 59

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Contents

1	Introduction	1028
2	Critically Appraising Systematic Reviews	1029
2.1	Tools for Appraising Systematic Reviews	1030
2.2	Important Questions to Ask when Appraising a Systematic Review	1030
2.3	Completeness and Quality of Reporting in Systematic Reviews	1034
3	Critically Appraising Experimental Studies (RCTs and Non-RCTs)	1035
3.1	Tools for Appraising Experimental Studies	1035
3.2	Important Questions to Ask when Appraising an Experimental Study	1036
3.3	Completeness and Quality of Reporting in Experimental Studies	1040

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4	Critically Appraising Observational Studies (Cohort, Case-control, and Cross-Sectional Studies)	1040
4.1	Tools for Appraising Observational Studies	1041
4.2	Important Questions to Ask when Appraising an Observational Study	1043
4.3	Completeness and Quality of Reporting in Observational Studies	1046
5	Conclusion and Future Directions	1046
	References	1047

Abstract

Critical appraisal skills are important for anyone wishing to make informed decisions or improve the quality of healthcare delivery. A good critical appraisal provides information regarding the believability and usefulness of a particular study. However, the appraisal process is often overlooked, and critically appraising quantitative research can be daunting for both researchers and clinicians. This chapter introduces the concept of critical appraisal and highlights its importance in evidence-based practice. Readers are then introduced to the most common quantitative study designs and key questions to ask when appraising each type of study. These studies include systematic reviews, experimental studies (randomized controlled trials and non-randomized controlled trials), and observational studies (cohort, case-control, and cross-sectional studies). This chapter also provides the tools most commonly used to appraise the methodological and reporting quality of quantitative studies. Overall, this chapter serves as a step-by-step guide to appraising quantitative research in healthcare settings.

Keywords

Critical appraisal · Quantitative research · Methodological quality · Reporting quality

1 Introduction

Critical appraisal describes the process of analyzing a study in a rigorous and methodical way. Often, this process involves working through a series of questions to assess the “quality” of a study by examining its strengths and limitations. A good critical appraisal should also explore whether or not a study’s findings can be applied to your own patient or clinical context. In this chapter, we will explore the critical appraisal process and provide you with the foundation required to start appraising quantitative research.

Critical appraisal skills are important for anyone wishing to make informed decisions or improve the quality of healthcare delivery. Not all studies are carried out using rigorous methods. Studies may be influenced by many types of bias, irrespective of their level of evidence. Just because something has been published does not mean that you can automatically trust its findings. Further, even if you can trust the study’s findings, it does not necessarily mean that they will be useful in your particular clinical situation. Critical appraisal skills are required to determine whether or not the study was well-conducted and if its findings are believable or useful.

Whenever a study is completed, there are three likely explanations for its findings (Mhaskar et al. 2009):

1. The study findings are correct and its conclusions are true. This is the ideal scenario but is not always the case.
2. The findings were due to random variation (chance). In any study, there is some degree of uncertainty, and we can never be absolutely sure that the results were not due to chance. Studies investigating larger groups of people are more likely to produce results that accurately reflect “reality,” rather than random variation. To conceptualize this, imagine you have thrown a dart toward a target and immediately hit the bullseye. It is difficult to determine whether or not this reflects your true skill level or was simply a “fluke.” If we were to record your performance following ten attempts, the average score across these attempts would give us a better idea of your overall skill level. There would be some random variation in these attempts, with you occasionally hitting above or below the bullseye. Increasing our number of recordings would give us an even more accurate reflection of your typical performance. Similarly, increasing the sample size of a study can “wash out” the influence of random variation.
3. The findings were affected by systematic error (bias). If the tail of your dart was bent, it may lead to you hitting well below the bullseye with every throw. In this case, we would be able to predict the direction of the result (above or below the bullseye) every time. This predictable, nonrandom error is known as bias. To an onlooker, a biased dart may make you appear to be a much better or worse dart player than you actually are. Increasing our number of recordings would not necessarily give us a better reflection of your true skill level. Likewise, increasing a study’s sample size may not eliminate systematic errors.

Deviations from “reality” can be caused by a number of problems throughout the design and execution of a study. Bias can obscure up to 60% of the real effect of a healthcare intervention (Mhaskar et al. 2009). Increasing evidence indicates that “biased results from poorly designed and reported trials can mislead decision-making in healthcare at all levels” (Moher et al. 2001, p. 29). Media attention and false credibility can further increase the influence of poorly conducted studies. Critical appraisal skills are essential when it comes to identifying biases and making informed decisions. In the following sections, we are going to step you through the process of critically appraising common quantitative study designs. We will provide you with tools that can be used to assist with this process, as well as examples of important questions to ask when appraising each type of study.

2 Critically Appraising Systematic Reviews

Systematic reviews occupy the highest level on the Australian National Health and Medical Research Council (NHMRC) hierarchy of evidence (National Health and Medical Research Council 2009). These studies collect and analyze multiple studies in order to provide a complete, exhaustive summary of the literature currently

available to answer a particular question. This literature should be obtained through transparent and reproducible database searches, based on predefined criteria (see also ► [Chap. 46, “Conducting a Systematic Review: A Practical Guide”](#)). However, as stated in the previous section, not all studies are conducted using rigorous methods. Although systematic reviews are considered to be a high level of evidence, they are not immune to biases and cannot be trusted by default. As with any study, there are three primary elements to consider when appraising a systematic review: the validity of the methodology, the size and precision of the effects, and the applicability of the findings to your specific client or population of interest (Hoffmann et al. [2013](#)).

2.1 Tools for Appraising Systematic Reviews

There are a number of tools that can be used to assist with critically appraising systematic reviews. For systematic reviews of intervention studies, commonly employed appraisal tools include:

- A measurement tool to assess systematic reviews (AMSTAR 2) (Shea et al. [2017](#))
- The Critical Appraisal Skills Program (CASP) checklist for systematic reviews (Critical Appraisal Skills Program [2017](#))
- The Joanna Briggs Institute’s critical appraisal tool for systematic reviews (Joanna Briggs Institute [2017](#))
- The Centre for Evidence-Based Medicine’s systematic review appraisal tool (Centre for Evidence-based Medicine [2017](#))
- The criteria proposed by Greenhalgh and Donald ([2000](#))

All of these tools provide checklists and guides designed to assist in critically appraising the methodological quality of systematic reviews and the extent to which they have addressed potential biases.

2.2 Important Questions to Ask when Appraising a Systematic Review

Table [1](#) presents a list of key questions to ask when appraising the methodological quality of a systematic review. These questions have been adapted from the AMSTAR 2 (Shea et al. [2017](#)), CASP (Shea et al. [2017](#)), and Greenhalgh and Donald ([2000](#)) checklists. In this section, we will explore each of these questions and provide examples to facilitate their application and interpretation. Note that the last two questions do not relate to methodological quality (which should always be considered first), and the results of a study should not influence your decision regarding the “best available” evidence. However, we have included these questions here in order to provide you with a holistic approach toward appraisal that will be most useful in clinical contexts.

Table 1 Important questions to ask when appraising a systematic review

1. Did the review address a clearly focused question?
2. Did the review have clearly defined eligibility criteria and select the most appropriate studies?
3. Does the review have a comprehensive literature search strategy?
4. Did the review include a risk of bias assessment?
5. Did the review perform a meta-analysis, and was it appropriate to do so?
6. What are the results of the review and how precise are they?
7. How relevant are the results to my patient or problem?

1. Did the Review Address a Clearly Focused Question?

Systematic reviews should clearly and concisely spell out their research question. A good research question will highlight the population of interest (P), the proposed intervention/issue (I), any comparison groups (C), as well as the outcomes being investigated (O). An example research question using this PICO format would be, “Is hand therapy (I) more effective than corticosteroid injections (C) in reducing pain levels (O) in people with de Quervain’s disease (a repetitive strain injury in the hand) (P)” (Cavaleri et al. 2016). Including timeframes, such as “over a 6-month period,” is also useful (see also ► [Chap. 46, “Conducting a Systematic Review: A Practical Guide”](#)).

2. Did the Review Have Clearly Defined Eligibility Criteria and Select the Most Appropriate Studies?

Reviews should include studies that address their research question and are of a robust design. Randomized controlled trials are usually most appropriate for evaluating interventions but may not always be appropriate for ethical reasons (see also ► [Chap. 37, “Randomized Controlled Trials”](#)). For example, it would not be ethical to conduct a randomized controlled trial investigating the effects of a substance known to cause harm (e.g., illicit drugs). In these cases, authors should explain why the study designs they have included are most suitable. To answer “yes” to this question, systematic reviews should also elaborate on their PICO in a section that discusses their inclusion and exclusion criteria. This section should highlight study designs, populations, interventions, comparisons, and outcomes that were eligible to be included in the review and those that were not. To minimize bias, more than one independent reviewer should be involved in selecting studies based on these criteria (Critical Appraisal Skills Program 2017; Joanna Briggs Institute 2017).

3. Does the Review Have a Comprehensive Literature Search Strategy?

This question helps us determine whether or not important articles may have been missed during the search for relevant literature. A good search strategy must be reproducible. To answer “yes” to this question, a systematic review should:

- Search at least two databases that are relevant to the research question.
- Provide a search strategy that includes synonyms for all search terms.
- Justify any publication restrictions, such as language.
- Search the reference lists of included studies. This is called “pearling” and is useful for finding articles that may have been missed by database searches (Hoffmann et al. 2013).

Ideally, systematic reviews should also search for unpublished papers (“gray literature”) to avoid publication bias. Publication bias occurs when journals selectively publish articles with significant findings. As studies with positive results are also more likely to be published in English, pooling data from English studies alone may lead to an overestimation of treatment effect (Higgins and Green 2009). Including non-English studies is, therefore, also beneficial in highlighting the true effect of a particular intervention.

4. Did the Review Include a Risk of Bias Assessment?

As with a good search strategy, a risk of bias assessment should be reproducible. Risk of bias assessments may incorporate the appraisal tools presented throughout this chapter. The risk of bias section is important in determining whether the articles included in the systematic review were of high quality. Note that you can answer “yes” to this question even if the studies included in the review were poorly designed, as long as the review has identified that this was the case. A systematic review can still have high methodological quality even if the only literature available for review was poor (i.e., we are critiquing the review itself and not necessarily the studies it found).

When reviewing randomized controlled trials, factors such as random allocation and blinding should be considered (see also ► Chap. 37, “Randomized Controlled Trials”). For all study designs, reproducible methods for assessing biases and confounding factors must be provided. A confounding factor refers to anything that may “mask” or confuse the true results of a study (Shea et al. 2017). For example, if you were investigating the effect of television viewing and eye damage, the association between these variables could be distorted if one group has a greater number of elderly individuals than the other. Television may appear to cause eye damage, but the confounding effect of age (which could also influence vision) makes it difficult to come to a definitive conclusion. More than one reviewer should perform risk of bias assessments according to a set of prespecified criteria (Critical Appraisal Skills Program 2017; Joanna Briggs Institute 2017). Situations where reviewers disagree should be resolved through discussion or consultation with an additional reviewer. Use of the Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) guideline is now encouraged (Guyatt et al. 2011). This is a method for summarizing the overall quality of the reviewed evidence, with ratings of “high,” “moderate,” or “low” being used to indicate how confident we can be in the findings of the included studies.

5. Did the Review Perform a Meta-analysis, and Was It Appropriate to Do so?

To answer “yes” to this question, systematic reviews should justify combining (or not combining) the data from different studies in the form of a meta-analysis. Heterogeneity, or the differences between studies, should be examined and potential sources of heterogeneity investigated and discussed. In systematic reviews, heterogeneity may be tested statistically using the I^2 statistic. Ideally, reviews should also examine how overall results vary with the inclusion or exclusion of studies that were judged to be at a high risk of bias (Hoffmann et al. 2013).

6. What Are the Results of the Review and How Precise Are They?

While the results of a study should not influence our decision regarding its methodological quality, an understanding of a systematic review’s results section is important when deciding to implement a particular intervention based on the best available evidence. Let us consider the forest plot and table below (see Fig. 1).

The first column from the left lists the studies (A, B, and C) that are included in the forest plot. The second and third columns present the number of people who recovered, as well as the total number of people included, in both the intervention and control groups for each study. Next is the risk ratio, which is a ratio describing the probability of an event (recovery) occurring in the intervention group versus the control group. Other ratios or mean differences between groups can also be presented in forest plots. While these values are useful in describing what happened in the actual study, they do not provide the whole picture in terms of the range of values that can be expected beyond the study setting. For this, we provide the 95% confidence interval (CI) in brackets next to each risk ratio. The confidence intervals tell us the range of results we could expect to see in the population, in this case with a 95% degree of certainty (precision). The weight column tells us how much “pull” or influence the study has over the combined results and is largely determined by its sample size.

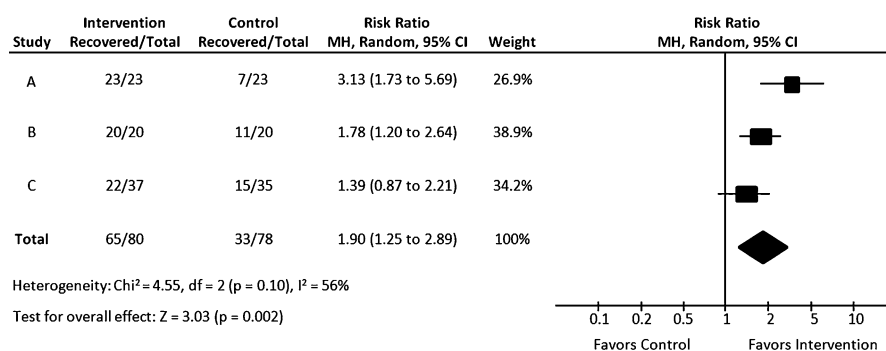


Fig. 1 Example forest plot

In the forest plot itself, each black square represents the intervention effect from the individual studies (A, B, and C). The horizontal lines either side of the black squares represent the 95% confidence intervals surrounding these results. As this plot is presenting ratio data, a value of 1 would indicate “no effect,” represented by the vertical line in the middle of the plot. Results to the right of this line favor the intervention, and results to the left of this line favor the control group. The diamond at the bottom of the plot is the summary statistic, which is a value that represents the overall effect when all of the study results are combined. The center of the diamond indicates the risk ratio (or other study effect result), and the width of the diamond represents the overall confidence interval. In this plot, we can see that the overall results favor the intervention. Being able to interpret such data is important when making clinical decisions.

7. How Relevant Are the Results to My Patient or Problem?

Finally, you should consider whether the findings of the review are applicable to your patient or population of interest. Is the study population similar to your particular case in terms of age, diagnosis, chronicity, etc.? Do you have access to the proposed interventions? How do the results fit in with the patient’s values and your own clinical experience? Another factor to consider is whether the results are strong enough to justify implementing the intervention. A good method of assessing this is by discussing a minimally important difference (MID) with your patient. The MID is the smallest improvement that your patient would consider worthwhile. If the systematic review indicates that, in the population, we can expect better improvements than that desired by your patient, we can say that the intervention is worth pursuing (“clinically significant”). If not, exploring other options may be worthwhile.

2.3 Completeness and Quality of Reporting in Systematic Reviews

There is an important distinction between methodological quality and reporting quality. Methodological quality is concerned with how well a study was designed and conducted (e.g., literature search, eligibility criteria, meta-analyses), while reporting quality describes how well these processes were described in the paper itself. Although a systematic review may have been conducted in a rigorous manner, it is not useful to the reader unless its methods and findings are sufficiently reported. There is a link between methodological quality and reporting quality in that research processes cannot be reported if they were not appropriately implemented in the first place. However, reporting quality also encompasses parts of the paper beyond the methods section. Thorough appraisals should, therefore, examine both methodological and reporting quality. Guidelines for assessing the reporting quality of systematic reviews have been developed to improve clarity and reduce research “waste” (Moher et al. 2009). The most popular tool used to assess reporting quality in

systematic reviews is the preferred reporting items for systematic reviews and meta-analyses (PRISMA) statement (Moher et al. 2009). The PRISMA provides a minimum set of items for reporting in systematic reviews, particularly those evaluating the effects of interventions. These items cover the title, abstract, introduction, methods, results, and discussion sections of systematic reviews. The meta-analysis of observational studies in epidemiology (MOOSE) group also offers guidelines for assessing the reporting quality of systematic reviews based on observational studies (Stroup et al. 2000).

3 Critically Appraising Experimental Studies (RCTs and Non-RCTs)

Experimental studies involve actively altering, rather than just observing, exposures or interventions of interest and assessing their impact over time. That is, in experimental studies, the independent variable is under the control of the researcher. Experimental studies are less susceptible to confounding and bias than other study designs because researchers can take measures to control certain variables (Dawes et al. 2005). However, experimental studies are by no means perfect, and strong critical appraisals are required before you decide to implement their findings.

3.1 Tools for Appraising Experimental Studies

There is a wide array of tools available to assist with critically appraising experimental studies. Some of the most commonly used appraisal tools include:

Randomized controlled trials

- The Physiotherapy Evidence Database (PEDro) scale (2017)
- The CASP RCT appraisal tool (Critical Appraisal Skills Program 2017)
- The Joanna Briggs Institute's checklist for RCTs (Joanna Briggs Institute 2017)
- The Jadad scale (Clark et al. 1999)
- The Centre for Evidence-Based Medicine's RCT appraisal tool (Centre for Evidence-based Medicine 2017)

Non-randomized (quasi-randomized) controlled trials

- The Joanna Briggs Institute's appraisal checklist for non-randomized controlled trials (Joanna Briggs Institute 2017)
- The Cochrane risk of bias in non-randomized studies of interventions (ROBINS-I) tool (Sterne et al. 2016)

All of these tools assess the extent to which experimental studies are internally valid. External validity, or applicability to “real-world” settings, is also covered by some of these tools.

3.2 Important Questions to Ask when Appraising an Experimental Study

There are eight questions that are commonly asked when appraising the potential risk of bias in experimental studies. These questions are summarized in Table 2 and are based upon criteria presented in the PEDro (2017) and CASP (2017) RCT appraisal tools. As always, it is also important to consider the study in the context of your specific patient or population of interest.

1. Was There a Control Group?

To appreciate the true effect of an intervention, comparison to a control group is required. A control group is a group of participants who are as similar as possible to the intervention group, except that they do not receive the intervention or exposure being investigated (Portney and Watkins 2009). Participants in the control group may instead be given no intervention or a placebo intervention. If participants are followed over time with no comparison to a control group, it is impossible to tell how much of the observed change is due to the effect of the intervention itself and how much is due to some other explanation (e.g., the placebo effect). Further, while participants in an uncontrolled study may improve following the intervention, there is nothing to say that they would not still have improved without it. Comparison to a control group is required to detect whether the intervention causes effects that would not otherwise be expected over time (Portney and Watkins 2009).

2. Was the Allocation of Participants to Groups Randomized?

Randomized controlled trials and non-randomized controlled trials differ in one very important regard – randomization. This process ensures that participants have an equal chance of being allocated to any group, meaning that potential differences

Table 2 Important questions to ask when appraising an experimental study

1. Was there a control group?
2. Was the allocation of participants to groups randomized?
3. Was the group allocation sequence concealed?
4. Were the groups similar at baseline?
5. Were the participants and study personnel blinded?
6. Was there adequate follow-up of participants and a sufficient completion rate?
7. Was an intention-to-treat analysis performed?
8. Were between-group statistical comparisons performed?

between groups should be minimal and due to chance only (Altman and Bland 1999; see also ► Chap. 37, “Randomized Controlled Trials”). Studies that do not employ randomization are at risk of having systematic differences between groups. In such cases, we may not be able to determine if it is the intervention, or some other factor, that is influencing the results. For example, if we were to allocate every male to the intervention group, and every female to the control group, we would not be able to determine if differences between the groups were actually due to the intervention or simply due to gender differences. Randomly allocating people to groups ensures that participant characteristics (including gender, age, weight, height, occupation, recreational activities, belief in the effect of the intervention, and so on) are evenly distributed throughout the intervention and control groups (Hoffmann et al. 2013). This means that any differences between groups at the end of the study are most likely a result of the intervention and not some other factor.

Random allocation can be done by using a random number generator, flipping a coin, or pulling names out of a hat. The simplest randomization process involves randomly allocating individuals or clusters of individuals (such as clinics, schools, or teams) to each group. Randomization can also be stratified, meaning that participants are matched as well as randomly allocated to groups. This approach ensures that confounding factors are balanced between groups. For example, when investigating the influence of a training intervention on athletic performance, participants could be stratified according to their skill level, belonging to either “beginner,” “intermediate,” or “advanced” categories. When randomization occurs, the researchers then make sure that there are equal numbers of people from each category in the intervention and control groups (Portney and Watkins 2009).

3. Was the Group Allocation Sequence Concealed?

Group allocation describes the process of assigning participants to either the intervention or control group. Adhering to the allocation sequence is important when it comes to maintaining the benefits of randomization (Altman and Bland 1999). If researchers know the group to which a person will be allocated (that is, the sequence is not ‘concealed’), they may think twice about including that person in the study or may interfere with the allocation process to ensure that a certain individual receives a particular intervention. This selective allocation of participants can introduce bias that affects the overall results (Moher et al. 2001). However, such problems can be avoided by concealing the allocation sequence. Allocation can be concealed by having the randomization sequence administered by someone who is not part of the study personnel (or is “off-site”). Opaque envelopes can also be used. In this case, the envelope, which has the participant’s allocated group inside, is not opened until after the participant has been enrolled in the study (Hoffmann et al. 2013).

4. Were the Groups Similar at Baseline?

Authors should provide information regarding important baseline characteristics so that readers can determine whether or not the groups were truly similar at

‘baseline’, or prior to the introduction of the intervention. This is crucial, because we need to be sure that differences between groups at the end of the trial were due to the intervention alone and not simply the result of baseline differences. Consider, for example, a study investigating the effect of meditation on student stress levels. If one of the groups had higher stress levels at the start of the study, then differences between the groups at the end of the study may be due to this initial difference, rather than the intervention itself.

While randomization is an important step, it cannot absolutely guarantee that groups will be similar, particular when small samples are being investigated. Studies should therefore present key demographic data (e.g., age, gender, height, weight) and baseline scores on key outcome measures (Roberts and Torgerson 1999). As a critical appraiser, it is up to you to determine which of these factors may influence the results, and whether or not the groups are sufficiently similar at baseline. If baseline differences are present, researchers should account for these differences during their statistical analyses. If they do not, you will need to consider the baseline differences when interpreting the results.

5. Were the Participants and Study Personnel Blinded?

Blinding refers to the process of ensuring that participants and study personnel (researchers and health professionals) involved in a study do not know the groups to which participants were allocated (Hewitt and Torgerson 2006; see ► [Chap. 37, “Randomized Controlled Trials”](#)). Blinding and allocation concealment are often confused. Allocation concealment involves not disclosing the allocation sequence *before* the patient is enrolled into the study, while blinding ensures that participants and study personnel do not know the treatment allocation *after* enrolment. This is important because people involved in studies will often have preconceived ideas or expectations about the effects of particular interventions. These expectations can affect their behavior and, in turn, the results of the study (Hewitt and Torgerson 2006). For example, a participant may stop putting in effort during assessments if they discover that they are part of the control group. Similarly, a participant who knows they are in the intervention group is likely to experience exaggerated improvements in line with their expectations (Hewitt and Torgerson 2006). The intervention and control groups should, therefore, be indistinguishable, with there being no way of participants or study personnel discovering the groups to which people were allocated until the end of the study.

Assessors, or the people taking measurements during a study, can usually be blinded during objective assessments. Ideally, an “independent assessor” is used. This describes a person who is unaware of a participant’s group allocation during baseline and follow-up assessments. However, health professionals and participants cannot always be blinded. Consider a study investigating the effects of aquatic physiotherapy on lower limb mobility in people with osteoarthritis. Both the participants and health professionals will know whether or not they are in the intervention (aquatic environment) or control (land-based environment) group. This factor would have to be taken into consideration when appraising the study and interpreting its results.

Experimental studies are often categorized according to the degree of blinding they employ. In a “single-blind” experiment, only the participants are blinded. During “double-blind” experiments, neither the participants nor the researchers know the groups to which participants belong. A “triple-blind” experiment involves the most rigorous form of blinding where none of the participants, researchers, or assessors know which participants are in the control group and which are in the intervention group.

6. Was There Adequate Follow-Up of Participants and a Sufficient Completion Rate?

It is not uncommon for participants to withdraw from studies or be unavailable for follow-up assessments. Such issues may introduce bias (Guyatt et al. 1993). For example, a situation in which ten participants were “lost to follow-up” due to changing occupations and moving away is vastly different to a situation in which ten participants were lost to follow-up because the intervention was making them ill. In the latter case, the overall results may favor the intervention simply because people who had negative side effects did not complete the study. This would mean that only people who improved or had no side effects were analyzed. Studies should, therefore, indicate clearly whether participants were properly accounted for, and why data may be missing for certain participants. As bias is increased when large numbers of participants withdraw from a study, various authors have suggested approaching studies with a completion rate of less than 85% with caution (Herbert et al. 2005; Dumville et al. 2006). Ideally, a diagram detailing the flow of participants through each stage of the study should be included alongside explanations for any participants lost to follow-up (Moher et al. 2001).

7. Was an Intention-to-Treat Analysis Performed?

Study participants may not always receive the intervention or control conditions as they were initially allocated. Imagine a study investigating the effectiveness of exercise in the treatment of knee pain. Some participants in the intervention group may not perform exercises as instructed due to a lack of motivation or excessive pain. In such cases, it may seem appropriate to analyze participants as if they were in the control group rather than the group to which they were actually allocated. However, doing so would increase the number of people in the control group who were unmotivated or had excessive pain (Hoffmann et al. 2013). This would undo the effects of randomization, leading to potentially unfair comparisons being made between groups. Likewise, we could not simply remove these participants from the analysis altogether as this would cause problems associated with incomplete follow-up. Instead, participants should be analyzed in the groups to which they were initially randomized, regardless of whether or not they remained in that group for the entire study. This principle is referred to as “intention-to-treat” analysis and is important in preserving the value of random allocation (Hoffmann et al. 2013).

8. Were Between-Group Statistical Comparisons Performed?

In an experimental study, the most valuable comparisons are between the intervention (or exposure) group and the control group. These between-group comparisons allow us to identify the extent to which the intervention has made a true impact. Consider a study investigating the effects of fruit consumption on the blood glucose levels of people with diabetes. If the intervention group's average blood glucose readings improved from baseline, it may be tempting to state that the intervention was successful based on this "within-group" information. However, by doing so, we would be ignoring the results of the control group entirely. Instead, our conclusions should be based on comparisons between the intervention and control groups at the end of the study, assuming that the groups were similar at baseline. Such information is far more valuable than performing within-group analyses, which are susceptible to many forms of bias.

3.3 Completeness and Quality of Reporting in Experimental Studies

The Consolidated Standards of Reporting Trials (CONSORT) statement provides a checklist for researchers and readers to assess the reporting quality of experimental studies (Moher et al. 2001). This statement does not assess the way in which the study was conducted but, rather, explores the quality of the reporting of these details within the paper itself. The template for intervention description and replication (TIDieR) checklist is a similar tool specifically designed for intervention studies (Hoffmann et al. 2014). The use of such tools is strongly recommended (and in most cases, compulsory) when submitting journal articles for publication. However, not all journals require authors to adhere to CONSORT or TIDieR recommendations, and many articles were published before these tools were created, so performing appraisals of reporting quality yourself is always a good idea.

4 Critically Appraising Observational Studies (Cohort, Case-control, and Cross-Sectional Studies)

During observational studies, the independent variable is not under the control of the researcher. These studies seek to observe the natural progression of a condition or response to treatment, without directly intervening or randomly allocating people to groups. As such, these studies are more susceptible to confounding and bias than experimental studies (Hoffmann et al. 2013). However, observational studies are particularly useful for situations in which experimental studies would not be ethical or practical, like when investigating potentially harmful exposures. To review, the main types of observational studies are:

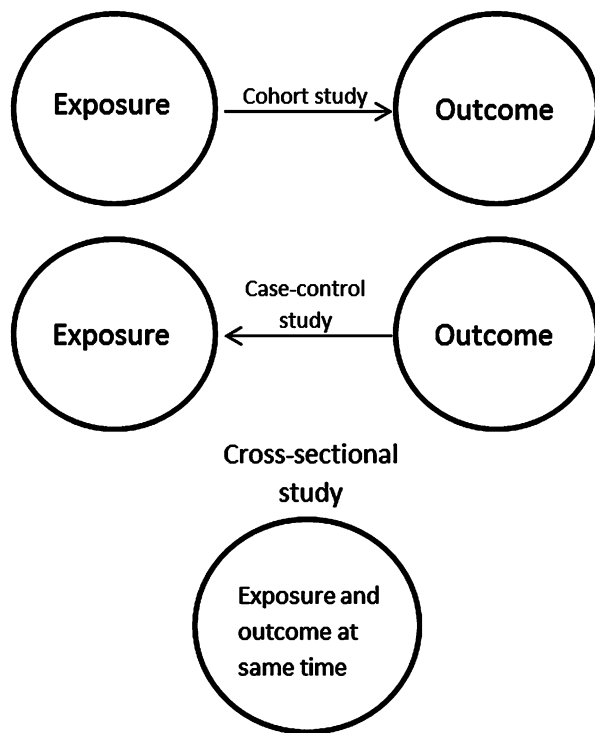
- **Cohort studies:** Cohort studies are a type of longitudinal study in which participants are followed over time (see also ► [Chap. 35, “Longitudinal Study Designs”](#)). Participants with certain characteristics or exposures (e.g., risk factors, conditions, behaviors) are labeled as a “cohort.” Following exposure, the cohort is followed for a period of time, outcomes are measured, and these outcomes are compared to the initial presentations of people in the cohort. Remember that exposure is not controlled by the researchers and would have occurred regardless of the study (unlike in experimental study designs). For example, a cohort study may involve identifying a group of mothers who recently starting breastfeeding and following them over time to observe if their children develop dental caries or tooth decay (Arora et al. 2011). Researchers would then identify differences between children who did or did not develop tooth decay in terms of factors such as parental health, feeding duration, and fluoride exposure.
- **Case-control studies:** Case-control studies are different to cohort studies in that they investigate participants who have experienced an outcome, “cases” (e.g., developing a disease, becoming injured), already. These participants are matched with similar participants, “controls” (for factors such as age, gender, and so on), who have not experienced that outcome. Case-control studies then compare the groups by looking-back and observing differences between them in terms of risk factors or exposures. For example, a case-control study may involve identifying people who already have lung cancer, matching them to people who do not, and then looking back to identify any differences in exposure to cigarette smoking. This design is not as robust as a cohort study as researchers are often not present when baseline data were collected, and the information regarding risk factors may be incomplete. Consider a study where the outcome was “death before the age of 50 years old” – researchers would need to rely on hospital records to identify risk factors, rather than collecting them from participants at baseline like in a cohort study.
- **Cross-sectional study:** Cross-sectional studies take a “snapshot” of a sample population at a single point in time and determine who has the outcome of interest. For example, a cross-sectional study may analyze a sample of current cigarette smokers and identify the proportion of people with early-stage lung cancer. The major advantage of this study design is that it is relatively inexpensive compared to cohort or case-control studies. However, cross-sectional studies require data on a particular subject to be readily available and routinely collected. The accuracy of this historical data cannot be guaranteed. Cross-sectional studies also provide no longitudinal information and so cannot produce claims as strong as other study types.

Figure 2 provides a summary of the main observation study types.

4.1 Tools for Appraising Observational Studies

Many tools are available to assist with the critical appraisal of observational studies. Some of these tools provide general guidelines, while others offer checklists specific to cohort, case-control, or cross-sectional studies. Many of the key appraisal items

Fig. 2 Overview of observational studies



overlap across these study types. As always, you should consider methodological quality in conjunction with the applicability of the results to your individual patient or population of interest. Commonly employed appraisal tools include:

Tools that combine study types

- The quality assessment tools for observational studies from the National Heart, Lung, and Blood Institute (2017). This site provides a combined tool to appraise cohort and cross-sectional studies and a separate tool to appraise case-control studies.
- The Centre for Evidence-Based Medicine’s prognostic and diagnostic study appraisal tools (Centre for Evidence-based Medicine 2017).

Cohort studies

- The CASP cohort study appraisal tool (Critical Appraisal Skills Program 2017)
- The Joanna Briggs Institute’s appraisal checklist for cohort studies (Joanna Briggs Institute 2017)
- The cohort study appraisal tool from the Center for Evidence-based Management (2017)

Case-control studies

- The CASP case-control study appraisal tool (Critical Appraisal Skills Program 2017)
- The Joanna Briggs Institute’s appraisal checklist for case-control studies (Joanna Briggs Institute 2017)
- The case-control study appraisal tool from the Center for Evidence-based Management (2017)

Cross-sectional studies

- The cross-sectional study appraisal tool from the Center for Evidence-based Management (2017)
- The Joanna Briggs Institute’s appraisal checklist for cross-sectional studies (Joanna Briggs Institute 2017)

Tools such as the quality assessment of diagnostic accuracy studies (QUADAS-2) are also available for observational studies focusing on the evaluation of diagnostic tools and techniques (Whiting et al. 2011).

4.2 Important Questions to Ask when Appraising an Observational Study

There are six questions that are commonly asked when appraising the potential risk of bias in observational studies. These questions are summarized in Table 3 and are derived from criteria presented in the CASP (2017) and Joanna Briggs Institute’s (2017) observational study appraisal tools.

1. Was a Clearly Focused Issue Addressed and Was an Appropriate Type of Study Used?

As with all studies, a good initial question to ask when appraising observational studies is whether a clearly focused issue was addressed. This is often considered a “screening question” along with asking if participants were recruited in an appropriate manner. Answering “no” to such questions indicates that a study is unlikely to be helpful and may not warrant further appraisal. Observational studies should use the PICO question format described in the systematic reviews section of this chapter (see also ► Chap. 46, “Conducting a Systematic Review: A Practical Guide”).

It is also important to identify whether the type of study adopted is suitable to address the issue presented by the authors. Questions concerning natural history and risk factors are best answered by cohort studies, but costs or disease rarity may make case-control or cross-sectional studies more suitable. Observational studies are also most suitable when the outcome is harmful because RCTs in this case would be unethical. As outlined in the previous section, questions regarding

Table 3 Important questions to ask when appraising an observational study

1. Was a clearly focused issue addressed and was an appropriate type of study used?
2. Were participants recruited in an appropriate manner?
3. Was the exposure measured in a valid and reliable manner?
4. Were confounding factors identified and taken into account?
5. Were the outcomes measured in a valid and reliable manner?
6. Was follow-up complete and long enough for outcomes to be observed?

treatment effectiveness would likely be better suited to experimental study types (see ► [Chap. 37, “Randomized Controlled Trials”](#)).

2. Were Participants Recruited in an Appropriate Manner?

This question explores whether or not a study’s sample is representative of the larger population of interest. “Generalizability” or “representativeness” is important in determining if a study’s findings may be applicable beyond the study setting and to our own patients (see also ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)). Observational studies should provide sufficient detail on their sample to allow readers to identify if it is applicable to their individual case or population of interest. Clearly defined inclusion and exclusion criteria are useful in highlighting the study’s target population.

Additional notes for cohort studies: In a cohort study, the odds of achieving a representative sample can be increased by recruiting all of the eligible patients (“consecutive cases”) who present to the recruitment site. Recruiting all eligible patients prevents bias that could be introduced if eligible patients were avoided or missed (Joanna Briggs Institute 2017). For case-control and cross-sectional studies, achieving a representative sample can be more difficult as researchers are limited to the data already available. During cohort studies, it is also important that participants are recruited at a consistent and well-defined stage of a condition’s progression. This is required because two people with the same condition can present with very different symptoms and experiences depending upon the length of time since their diagnosis (Hoffman et al. 2013). When participants are recruited at a consistent point early in their disease progression, the cohort is known as an “inception cohort.” Many studies that recruit individuals upon diagnosis label their participants as an inception cohort. However, as highlighted by Hoffman et al. (2013, p. 173), certain people may receive their initial diagnosis further into their disease progression than others. You, as the critical appraiser, must therefore consider carefully whether a true inception cohort has been obtained.

Additional notes for case-control studies: In a case-control study, the case and control groups should be as similar as possible, apart from the presence of the disease or exposure of interest. This is usually done by individually matching controls to each case on the basis of certain characteristics.

3. Was the Exposure Measured in a Valid and Reliable Manner?

The validity of an exposure measurement relates to its ability to assess what it is intended to assess. This is usually determined by comparing the measure to a “gold

standard” that is already known to be accurate. Reliability refers to the reproducibility of the measure’s results over time and between assessors. To allow the reader to determine whether the exposure was measured appropriately, observational studies should clearly outline the method with which the exposure was measured (Joanna Briggs Institute 2017). For a study in which the exposure was “visiting a trained herbalist during a marathon preparation,” it would be important to provide clear and reproducible definitions of “trained herbalist” and “marathon preparation.” Wherever possible, objective criteria should be applied to minimize bias (see ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)).

4. Were Confounding Factors Identified and Taken into Account?

Confounding factors describe anything that can become confused with the outcome of interest and bias the results. Most often, this occurs when there are differences between comparison groups (apart from the exposure of interest). Common confounders include baseline characteristics, prognostic factors (e.g., severity of condition, age of diagnosis, comorbidities), or concomitant exposures (e.g., smoking) (Joanna Briggs Institute 2017). Further explanation of confounding factors can be found in Sect. 2.2 of this chapter. Observational studies should identify potential confounders and employ strategies to account for their influence. This is often done by reporting the results of various subgroups of participants (e.g., smokers, non-smokers). Statistical techniques can be employed to adjust for subgroup analyses (see also ► [Chap. 54, “Data Analysis in Quantitative Research”](#)).

5. Were the Outcomes Measured in a Valid and Reliable Manner?

Although not always possible, outcomes are ideally assessed using objective criteria. As with exposure measurements, outcomes should be measured using previously validated definitions or diagnostic criteria. Once the objectivity, validity, and reliability of the outcome measure have been established, we should then explore the means by which measurements were conducted. We can look for information regarding the level of expertise of the assessors or the number of assessors involved in taking measurements (Joanna Briggs Institute 2017). A larger number of assessors may decrease the reliability of our recordings, particularly if they do not have similar levels of experience with the assessment tools (see ► [Chap. 38, “Measurement Issues in Quantitative Research”](#)).

6. Was Follow-Up Complete and Long Enough for Outcomes to Be Observed?

It is important for observational studies to run long enough (or look back far enough) to demonstrate an association between the exposure and the outcome. You, as the critical appraiser, must use your knowledge of the condition of interest to determine whether or not the follow-up period was long enough to allow clinically meaningful changes to occur (see ► [Chap. 35, “Longitudinal Study Designs”](#)).

Clinical practice guidelines, clinical research, and expert opinions can be useful in guiding your decision. Cross-sectional studies by design have no follow-up, so this question would not be considered when appraising that type of research.

4.3 Completeness and Quality of Reporting in Observational Studies

As outlined in the systematic review and experimental study sections of this chapter, a well-reported study can simplify the critical appraisal process. The reporting standard for observational studies is known as the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement (Von Elm et al. 2014). There are STROBE checklists available for observational studies in general, as well as statements designed specifically for cohort, case-control, and cross-sectional studies. The reporting quality of studies exploring diagnostic accuracy can be assessed using the Standards for Reporting Diagnostic Accuracy Studies (STARD) checklist (Bossuyt et al. 2003).

5 Conclusion and Future Directions

Not all studies are carried out using rigorous methods. Studies may be influenced by many types of bias, irrespective of their level of evidence. Critical appraisal skills are important for anyone wishing to make informed decisions or improve the quality of healthcare delivery. Important questions to ask during critical appraisals include:

For systematic reviews:

1. Did the review address a clearly focused question?
2. Did the review have clearly defined eligibility criteria and select the most appropriate studies?
3. Does the review have a comprehensive literature search strategy?
4. Did the review include a risk of bias assessment?
5. Did the review perform a meta-analysis, and was it appropriate to do so?
6. What are the results of the review and how precise are they?
7. How relevant are the results to my patient or problem?

For experimental studies:

1. Was there a control group?
2. Was the allocation of participants to groups randomized?
3. Was the group allocation sequence concealed?
4. Were the groups similar at baseline?
5. Were the participants and study personnel blinded?
6. Was there adequate follow-up of participants and a sufficient completion rate?

7. Was an intention-to-treat analysis performed?
8. Were between-group statistical comparisons performed?

For observational studies:

1. Was a clearly focused issue addressed and was an appropriate type of study used?
2. Were participants recruited in an appropriate manner?
3. Was the exposure measured in a valid and reliable manner?
4. Were confounding factors identified and taken into account?
5. Were the outcomes measured in a valid and reliable manner?
6. Was follow-up complete and long enough for outcomes to be observed?

A well-reported study can simplify the critical appraisal process, and there are also a number of tools available to assess reporting quality. This is distinct from methodological quality and focusses on the way in which study processes were described in the paper, rather than the actual study processes themselves. A good critical appraisal should assess a study's methodological and reporting quality, as well as the applicability of the results to one's own patient or clinical context.

Moving forward, make sure to use the skills you have acquired throughout this chapter in order to effectively appraise and implement the findings of quantitative research. Refining your critical appraisal skills will allow you to effectively identify relevant and rigorously conducted literature, saving you time and maximizing your treatment effectiveness. With the continuing acceleration of the healthcare research movement, employing strong critical appraisals will ensure that your patients can be confident that you are providing them with the best treatment options currently available.

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Appraising Mixed Methods Research

60

Elizabeth J. Halcomb

Contents

1	Introduction	1052
2	Critically Appraising Mixed Methods Research	1052
2.1	Mixed Methods Appraisal Tool (MMAT)	1054
2.2	Bespoke Quality Framework for Mixed Methods Research	1057
2.3	Central Criteria for Appraisal of Mixed Methods Research	1062
3	Conclusion and Future Directions	1064
	References	1065

Abstract

There is increasing interest in the use of mixed methods research approaches among health researchers. While mixed methods research has the potential to reveal rich data and deeper understandings of complex phenomena, it needs to be evaluated with the same level of critical appraisal as other methodologies. To date, however, much of the discourse around the critical appraisal of mixed methods research has discussed the challenges and considerations underlying critical appraisal. There has been limited agreement reached on optimal methods of evaluating this body of literature. This chapter will synthesize the literature on critically appraising mixed methods research and provide advice to those reviewing mixed methods papers around considerations in critical appraisal for this type of research.

Keywords

Mixed methods research · Critical appraisal · Methodological quality · Reporting quality

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1051

1 Introduction

Critical appraisal of any research is important in order to evaluate the “quality” and rigor of the study (Heyvaert et al. 2013). Understanding the quality of research will inform decisions about utilizing its findings in policy, education, and practice. While some limitations will be acceptable or unavoidable in a particular study, given its design, others may impact the utility of the findings and their transferability into practice.

In recent years, a series of checklists and tools have proliferated to guide the researcher in critically appraising the various research methodologies. Most of these tools are specifically designed for the evaluation of research that uses a particular study design. For example, the Critical Skills Appraisal Program (CASP) (2017) comprises eight tools that guide the evaluation of systematic reviews, randomized controlled trials, cohort studies, case control studies, economic evaluations, diagnostic studies, qualitative studies, and clinical prediction rule. Additionally, other tools have also emerged to define the reporting criteria for different types of research (Collins et al. 2012). For example, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al. 2009) guidelines inform reporting of systematic reviews of randomised controlled trials, while the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007) have become the standard for reporting qualitative research. It is important to remember that these latter tools focus on the quality of information describing the study. So, while they also reflect the quality of the research, they predominately reflect the quality of the writing rather than the study conduct (Souto et al. 2015). It is important, therefore, that the user understands the purpose of the tool to ensure that they are using it for the purpose which it was intended.

The need to critically appraise mixed methods studies is as important as the appraisal of either purely qualitative or quantitative research. Just because a single study has used both qualitative and quantitative aspects, it is not necessarily robust or rigorous (Bryman 2006b; Lavelle et al. 2013). While the issue of quality in mixed methods research has been long debated, it remains a contentious issue (O’Cathain 2010; Heyvaert et al. 2013; Barnat et al. 2017; MacInnes 2009). The evaluation of mixed methods research faces a number of issues beyond those of pure qualitative or quantitative research (O’Cathain et al. 2008; Fàbregues et al. 2018; Collins et al. 2012; MacInnes 2009). These issues stem from the underlying paradigmatic tensions of mixing methods, as well as variations in methodology and methods (Sale and Brazil 2004; Bryman 2006b). This chapter will discuss the tools that have been developed to guide the appraisal of mixed methods research and explore the issues that need to be considered when evaluating mixed methods research.

2 Critically Appraising Mixed Methods Research

Three alternatives have been suggested for the critical appraisal of mixed methods research (Bryman 2006b; O’Cathain 2010; Collins et al. 2012; Heyvaert et al. 2013). Firstly, convergent criteria have been proposed, whereby the same broad criteria are

used to evaluate both the quantitative and the qualitative components of the research. O’Cathain (2010) identified various simple and quick generic tools that can be used for critical appraisal regardless of study design. While these tools can be useful to provide a quick and broad evaluation, they are often too generalist to provide discrimination of quality and overlook the quality issues specific to mixed methods research.

Secondly, the individual component approach has been proposed, whereby the quantitative and the qualitative components are each evaluated in isolation based on their individual methodology or method (Dellinger and Leech 2007; O’Cathain 2010; Collins et al. 2012; Heyvaert et al. 2013) (see ► [Chaps. 58, “Appraisal of Qualitative Studies,”](#) and ► [59, “Critical Appraisal of Quantitative Research”](#)). An example of this kind of generic tool is the mixed methods appraisal tool (MMAT) discussed in detail below (Pace et al. 2012). Despite the logic that sound qualitative and quantitative components together strengthen the quality of a mixed methods study, the quality of one or other components may be adversely affected by its inclusion in a mixed methods investigation (O’Cathain 2010). In addition to the risk of underresourcing, underdeveloping, or underanalyzing one or other components, this method of appraisal ignores the fact that inferences are drawn from the whole study rather than just each component in isolation (O’Cathain 2010).

While both the convergent and individual component approaches do indeed provide critique of the qualitative and quantitative components that comprise the mixed methods study, they fail to capture the complexity of the integration that characterizes the mixed methods approach (Sale and Brazil 2004; Heyvaert et al. 2013; Barnat et al. 2017; Fàbregues et al. 2018). Therefore, in more recent years, attempts have been made to develop the bespoke tools, suggested as the third alternative for mixed methods quality appraisal (Bryman 2006b; O’Cathain 2010). These tools seek to capture both the individual considerations of the qualitative and quantitative methods and the considerations of mixing these in a single study. To date, however, consensus around a particular tool has not been reached. The most widely accepted tools, however, are discussed in more detail in subsequent sections (Sect. 2.1).

Fàbregues et al. (2018) have identified three key limitations in the current work around bespoke quality appraisal tools in mixed methods research. Firstly, most of the frameworks that have been developed have been based on the authors’ personal views of what constitutes quality, rather than being empirically derived. Therefore, the personal preferences and ways of thinking of these individuals have likely shaped the tools that have been developed (Collins et al. 2012; Heyvaert et al. 2013). Secondly, the professional discipline of the researcher is likely to impact on their practices and thinking as well as their understanding of quality in research (O’Cathain 2010; Collins et al. 2012; Fàbregues et al. 2018). While “research quality is not a homogeneous concept” (Fàbregues et al. 2018, p. 3) and is perceived somewhat differently by researchers across disciplines, it does have a number of common properties (Sale and Brazil 2004; O’Cathain 2010). However, given the expansion of mixed methods across health services and related disciplines beyond those of the researchers who have developed the current quality criteria, it is

important that efforts are made to ensure that criteria are relevant to mixed methods research across disciplines.

The final limitation is that the focus in the debate around quality in mixed methods research has been around the operationalization rather than conceptualization of quality criteria (Heyvaert et al. 2013; Fàbregues et al. 2018). So, while the focus has been on developing criteria to appraise mixed methods research, there has been little attention on researchers' conceptualization of quality in this methodology.

Despite calls to develop consensus in terms of quality appraisal criteria for mixed methods research (O'Cathain et al. 2008), others have identified that, given the heterogeneity of mixed methods research, a single set of quality criteria may not suit all studies (Bryman 2006b; O'Cathain 2010; Heyvaert et al. 2013). Proponents of this argument advocate that quality appraisal of mixed methods research should be guided by core criteria that reflect the most important aspects of mixed methods research and which can accommodate a range of different contexts, alternate designs, creativity, and various disciplinary foci (Sale and Brazil 2004; O'Cathain 2010; Bryman 2014; Fàbregues et al. 2018). Therefore, consideration of the basic principles of quality and the specific attributes of each study are required to ensure that the research is evaluated appropriately. In the absence of agreement, this chapter, I will present both a comprehensive bespoke quality framework (O'Cathain 2010) (see Sect. 2.2) and a set of broad bespoke quality criteria (Bryman 2014) (see Sect. 2.3) to allow the reader to see the various strategies for critical appraisal of mixed methods research. This will provide insight to inform the readers understanding of the complexity of critical appraisal in this methodology. It will also demonstrate that despite similarities, consensus has not been reached on a single quality evaluation approach that will suit all circumstances.

2.1 Mixed Methods Appraisal Tool (MMAT)

The MMAT was developed to facilitate the appraisal of mixed methods research within mixed studies reviews (Pluye et al. 2011; Pace et al. 2012; Souto et al. 2015) (see Table 1). The tool comprises five sets of criteria, namely:

- (i) Qualitative set
- (ii) Randomized controlled set
- (iii) Non-randomized set
- (iv) Observational descriptive set
- (v) Mixed methods set

Each of the first four sets of criteria can be used for either a single study of that design or a specific component of a mixed methods study. The final, mixed methods, set of criteria focuses on mixed methods research only. So, for example, a mixed methods study that combines a randomized trial of an intervention and interviews with participants would utilize three sets of criteria, that is, the randomized controlled set, the qualitative set, and the mixed methods set. While the quality score

Table 1 Mixed methods appraisal tool (Pluye et al. 2011; Pace et al. 2012)

Types of mixed methods components or primary studies	Quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	<p>Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?</p> <p>Do the collected data allow to address the research question (objective), for example, consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components)?</p> <p>Further quality appraisal may be not feasible when the answer is "No" or "Can't tell" to one or both screening questions.</p>				
Qualitative	<p>1.1 Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?</p> <p>1.2 Is the process for analyzing qualitative data relevant to address the research question (objective)?</p> <p>1.3 Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?</p> <p>1.4 Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?</p>				
Randomized controlled	<p>2.1 Is there a clear description of the randomization (or an appropriate sequence generation)?</p> <p>2.2 Is there a clear description of the allocation concealment (or blinding when applicable)?</p> <p>2.3 Are there complete outcome data (80% or above)?</p> <p>2.4 Is there low withdrawal/dropout (below 20%)?</p>				
Non-randomized	<p>3.1 Are participants (organizations) recruited in a way that minimized selection bias?</p> <p>3.2 Are measurements appropriate (clear origin, or validity known, or standard instrument, and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?</p> <p>3.3 In the groups being compared (exposed vs. nonexposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers</p>				

(continued)

Table 1 (continued)

Types of mixed methods components or primary studies	Quality criteria	Responses			
		Yes	No	Can't tell	Comments
	take into account (control for) the difference between these groups? 3.4 Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
Observational descriptive	4.1 Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)? 4.2 Is the sample representative of the population understudy? 4.3 Are measurements appropriate (clear origin, or validity known, or standard instrument)? 4.4 Is there an acceptable response rate (60% or above)?				
Mixed methods	5.1 Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)? 5.2 Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)? 5.3 Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design? Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied				

derived from implementing the MMAT is not considered informative (Pace et al. 2012), the description of study quality gained from utilizing the criteria is more useful to inform the reader about quality issues. If the quality score is used in mixed methods studies, Pace et al. (2012) advocate that the lowest score on the subscales that make up the study component should be considered the quality score. The rationale for this is that the overall study cannot be any stronger than its weakest component. While the MMAT has been fairly recently developed, reliability testing

has demonstrated that this tool is efficient and shows promising reliability (Pluye et al. 2011; Pace et al. 2012; Souto et al. 2015).

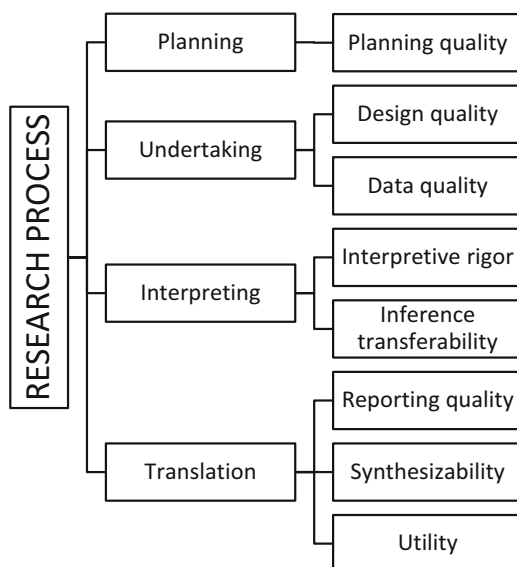
2.2 Bespoke Quality Framework for Mixed Methods Research

Various groups have described different approaches for evaluating the quality of mixed methods research (Onwuegbuzie and Johnson 2006; O’Cathain et al. 2008; Tashakkori and Teddlie 2008; Teddlie and Tashakkori 2009; Creswell and Plano Clark 2018). However, O’Cathain (2010) synthesized this into a comprehensive 44 criteria of quality framework. An adapted version of this framework is presented in Fig. 1. This framework delineates eight domains, across four stages of the research process, which need to be considered when evaluating the quality of a mixed methods study. Each domain is composed of a number of specific items, each of which is discussed in detail below. While this framework is perhaps the best attempt to date to synthesize the literature around mixed methods quality appraisal into a coherent framework, the large number of items and degree of overlap between concepts impact its utility in critical appraisal (Heyvaert et al. 2013). It is presented here to provide the reader with an overview of the key concepts and complex interrelationship between quality factors inherent in mixed methods studies.

2.2.1 Planning Phase

This first domain encompasses how well the mixed methods study has been planned and focuses on considerations that should be demonstrated within the mixed methods research proposal. Firstly, the *foundational element* of a comprehensive, critical

Fig. 1 Mixed methods quality framework. (Adapted from O’Cathain 2010)



literature review that situates the research question and study within a context is required to justify the choice of design (Dellinger and Leech 2007; O’Cathain 2010). Secondly, a clear justification of the choice of a mixed methods approach provides *rationale transparency*. This can highlight whether the approach has been selected for its intrinsic value or strategic purposes (e.g., attaining funding) (O’Cathain et al. 2007b). In cases where the justification is strategic, there is greater potential for neglect of one of the study components, lack of attention toward integration and lack of meta-inferences drawn from the whole study data (O’Cathain 2010).

Planning transparency refers to the clarity within the proposal around reporting the details of key aspects across research process. This includes aspects such as the paradigm, design, data collection plan, analysis methods, and integration approaches to be used.

Proposals of mixed methods research raise a number of issues around *feasibility*. Firstly, some mixed methods proposals demonstrate lack of researcher knowledge and experience by proposing components that are not feasible within the project time frame or resources (Halcomb and Andrew 2009). Additionally, in sequential studies, sufficient time may not be available or set aside within the proposed project time frame to complete all components (Halcomb and Andrew 2009). Limitations around feasibility have the potential to significantly impact on project quality.

2.2.2 Undertaking Phase

Within the conduct of the research, there are two domains of quality that should be considered. O’Cathain (2010) separates evaluation of the research design from that of data collection (see Fig. 2). Firstly, the design quality domain evaluates the rigor of the mixed methods study design, before the data quality domain appraises the processes of data collection and analysis.

Design Quality

In terms of design quality, there are four criteria that need to be considered (O’Cathain 2010). Firstly, there is *design transparency* (Tashakkori and Teddlie 2008; O’Cathain 2010). While a mixed methods study must comprise quantitative and qualitative components within the single study and some form of integration of these components, the specific design used should be clearly defined (MacInnes 2009).

Fig. 2 Quality criteria for undertaking research phase

Undertaking	Design quality	Design transparency
		Design suitability
		Design strength
		Design rigor
	Data quality	Data transparency
		Data rigor/design fidelity
		Analytic adequacy
		Analytic integration rigor

Researchers can draw upon the range of “conventional” designs proposed for mixed methods research (see ► [Chaps. 4, “The Nature of Mixed Methods Research,”](#) and ► [40, “The Use of Mixed Methods in Research”](#)). In some cases, these may need to be adapted to the specific study. It is important, however, that aspects such as the sequencing of methods, priority of various components, and the stage of integration are clearly defined and explained (O’Cathain [2010](#); Collins et al. [2012](#)).

Secondly, *design suitability* refers to the appropriateness of the chosen design to be congruent with the stated purpose of the study and to answer the specific research questions (Collins et al. [2012](#)). The design must also be aligned appropriately to the stated paradigm. For example, in a study where the purpose of the interviews is to build upon the survey findings, it is not appropriate to have a concurrent design as it is necessary to have at least undertaken preliminary survey analysis in order for the interviews to ask questions to deepen the understanding of survey findings. In this case a sequential design would clearly be more appropriate.

Design strength focuses upon the extent to which the strengths of each of the qualitative or quantitative components of the study compensates for the weaknesses in the other component (Tashakkori and Teddlie [2008](#); O’Cathain [2010](#)). For example, combining interviews or focus groups with survey data allows the richness of the qualitative interviews to provide depth to the large-scale survey findings.

The final consideration is *design rigor*, whereby consideration is given to whether the researcher stays true to the elements of the design in the implementation of the research methods. For example, if insufficient time is available to analyze the first phase of a sequential design, the second phase may not have sufficient understandings of the initial data to adequately build on the data (Halcomb and Andrew [2009](#)).

Data Quality

O’Cathain ([2010](#)) identifies five criteria which comprise the domain of data quality. Firstly, *data transparency* refers to the adequacy of the description of the data collection methods. Such description should include specific details about the participant recruitment, data collection methods, sample size, and analysis techniques (Creswell and Plano Clark [2007, 2011, 2018](#)). The reader should be able to understand what is being done in enough detail for them to be able to plausibly replicate the work. Stemming from the data transparency is *data rigor*. This refers to the rigor of the implementation of the research methods. Consideration should be given to whether any compromises in the rigorous conduct of each of the study components have been made to accommodate the mixed methods nature of the study (Dellinger and Leech [2007](#)). For example, have any phases in a sequential study been cut shorter than would be considered reasonable in a single method study to fit the project within a constrained time frame?

The subsequent three criteria focus on specific aspects of the research process. *Sampling adequacy* refers to the appropriateness of the sampling method and sample size for each component of the research (Tashakkori and Teddlie [2008](#); O’Cathain [2010](#)). As in single method studies, a sample size that is too small may impact on the inferences that can be made from the data. A further consideration in mixed methods studies is that the relationship between the sampling in each component should be clear to the reader.

Also important to evaluate is the *analytic adequacy* to ensure that the data analysis techniques are appropriate to both answer the research question and be coherent with the design and methods used (Collins et al. 2012). A key, but often largely forgotten, characteristic of mixed methods research is the integration of components (Halcomb and Hickman 2015). *Analytic integration rigor* refers to the quality of integration undertaken within the analysis phase of the study. While not all mixed methods studies integrate data at this stage, consideration of any integration should be included in any quality evaluation. Integration undertaken in the analysis stage may involve transformation of qualitative to quantitative data or using the findings of one component to inform the subsequent component (Andrew et al. 2008, 2011). In recent years, there has been greater attention paid to integration in the literature, and several authors offer strategies to guide integration methods (Andrew et al. 2008, 2011; O’Cathain et al. 2010; Halcomb and Hickman 2015).

2.2.3 Interpretation Phase

The quality of the inferences made from any study and the transferability of results are vital for readers in order to determine if the findings are sufficiently credible and trustworthy to inform practice and policy (Tashakkori and Teddlie 2008; O’Cathain 2010; Collins et al. 2012). Therefore, the quality of the interpretation phase can be evaluated by combining evaluation of interpretive rigor, the degree to which the conclusions are based on the findings, and inference transferability, or the extent to which findings can be applied in other contexts (Tashakkori and Teddlie 2008; O’Cathain 2010) (see Fig. 3).

Interpretive Rigor

Interpretation in mixed methods research involves the creation of what Tashakkori and Teddlie (2008) describe as “meta-inferences.” That is, the conclusions drawn extend beyond the findings of each component of the study to provide an

Fig. 3 Quality criteria for interpretative phase

Interpreting	Interpretive rigor	Interpretive transparency
		Interpretive consistency
		Theoretical consistency
		Interpretive agreement
		Interpretive distinctiveness
		Interpretive efficacy
		Interpretive bias reduction
		Interpretive correspondence
Inference transferability		Ecological transferability
		Population transferability
		Temporal transferability
		Theoretical transferability

overarching “meta-inference” or broad conclusions that overlay both the qualitative and qualitative findings (Collins et al. 2012). O’Cathain (2010) identifies eight criteria for evaluating interpretive rigor in mixed methods research. *Interpretive transparency* refers simply to the ability for the reader to follow which findings have emerged from the various components of the study (Teddlie and Tashakkori 2009). For example, in a study that combines interviews and survey data including open-ended questions, it should be clear to the reader which data collection method each data element is drawn from.

In addition to being able to follow the trail from data collection to specific study findings, *interpretive consistency* considers whether the conclusions drawn are consistent with the reported findings (Creswell and Plano Clark 2007; Greene 2007). Similarly, *theoretical consistency* refers to whether the conclusions drawn are consistent with contemporary understandings of the topic area (Dellinger and Leech 2007). This concept is similar to face validity where others can read the conclusions and deem them credible and reasonable when compared to what is known. Additionally, *interpretive agreement* refers to whether readers are likely to reach the same conclusions as the researcher (Creswell and Plano Clark 2007; Greene 2007; Collins et al. 2012). This can be demonstrated through strategies such as external peer review or member checking.

Teddlie and Tashakkori (2009) also highlight the need to consider *interpretive bias reduction*. This refers to the need to explore consistency and contradiction between the findings of different study components. If contradictory findings emerge, clear evidence should be available to demonstrate consideration of the potential impact of bias related to the particular method as a plausible explanation of the contradiction (O’Cathain 2010; Creswell and Plano Clark 2007, 2011, 2018).

In contrast, *interpretive distinctiveness* refers to the degree to which the conclusions drawn by the researchers are more credible than other plausible inferences (Collins et al. 2012). To this end, researchers should demonstrate that other possible interpretations are less plausible than their interpretation.

Interpretive efficacy relates to the adequacy with which the overall study conclusions incorporate the inferences of the qualitative and quantitative components of the study (Greene 2007; Teddlie and Tashakkori 2009; O’Cathain 2010; Collins et al. 2012). Achieving the right balance of the conclusions from each dataset is complex and requires skill on the part of the research team.

Consideration of how well the inferences flow from the initial study purpose and research question is termed *interpretive correspondence* (O’Cathain 2010). As in single method studies, it is important that the conclusions actually flow logically from the study purpose and address the initial research questions (MacInnes 2009).

Inference Transferability

In the same way that external validity and transferability demonstrate quality for quantitative and qualitative research respectively, *inference transferability* refers to the ability to apply the conclusions of the mixed methods research into another setting or context (Teddlie and Tashakkori 2009; O’Cathain 2010). Teddlie and Tashakkori (2009) describe transferability being evaluated in four ways, namely:

1. Ecological – to other contexts and practice settings
2. Population – to different participant groups
3. Temporal – to a point in the future
4. Theoretical – to other methods of measuring outcomes

2.2.4 Dissemination Phase

Dissemination is an important indicator of study quality as it reflects the conclusions drawn from the study findings and communication of these to the target audience. *Report availability* provides evidence of the completion of the project as proposed within the available resources and time frame (Tashakkori and Teddlie 2008; O’Cathain 2010). Importantly, in addition to report availability, *yield* refers to the additional insight and knowledge gained from a mixed methods study above that which would have been gained from either component in isolation (O’Cathain et al. 2007a). A low yield will be seen in studies that undertake limited integration or where the design fails to optimally overcome the weakness in one method with the strength of the other. The explicit reporting of key aspects of the study, including the integration, is evaluated under the *reporting transparency* criteria (O’Cathain 2010). Perhaps the most well-recognized tool for reporting quality in mixed methods research is the “Good Reporting of A Mixed Methods Study” (GRAMMS) tool (see Box 1). This was developed by O’Cathain et al. (2008) from a review of 118 mixed methods studies funded between 1994 and 2004 by the English Department of Health, which explored the quality of mixed methods research and identified current standards of reporting. Rather than being a checklist, this tool provides broad guidance around transparency in reporting mixed methods research.

Box 1 Good Reporting of a Mixed Methods Study (O’Cathain et al. 2008)

1. Describe the justification for using a mixed methods approach to the research question
2. Describe the design in terms of the purpose, priority, and sequence of methods
3. Describe each method in terms of sampling, data collection, and analysis
4. Describe where integration has occurred, how it has occurred, and who has participated in it
5. Describe any limitation of one method associated with the present of the other method
6. Describe any insights gained from mixing or integrating methods

2.3 Central Criteria for Appraisal of Mixed Methods Research

In contrast to the complex framework for critical appraisal proposed by O’Cathain (2010), Bryman (2014) proposes a much broader set of six central criteria for the evaluation of mixed methods research. Unlike the comprehensive framework described by O’Cathain (2010), these criteria very broadly identify the key

considerations in critically appraising mixed methods research. The broader nature of these considerations makes them more accessible to research consumers seeking to evaluate reports of mixed methods studies. However, understanding the range of issues explicated by O’Cathain (2010) puts these broad criteria into context.

Box 2 Criteria for Appraising Mixed Methods Research (Bryman 2014)

- Need for the quantitative and qualitative components to be implemented in a technically competent manner
- Need for transparency
- Need for mixed methods to be linked to research questions
- Need to be explicit about the nature of the mixed methods design employed
- Need for a rationale for the use of mixed methods research
- Need for integration

2.3.1 Need for the Quantitative and Qualitative Components to Be Implemented in a Technically Competent Manner

There is little argument that the various elements of quantitative and qualitative research need to be executed rigorously across the research process from sampling, instrument design, and implementation to data collection and analysis and interpretation (Tashakkori and Teddlie 2010; Creswell and Plano Clark 2011). This requires mixed methods researchers or at the very least research teams, to have broad skills across both quantitative and qualitative techniques (Halcomb and Andrew 2009; Bowers et al. 2013). Tools to evaluate these two components are well established in the literature (see ► Chaps. 58, “Appraisal of Qualitative Studies,” and ► 59, “Critical Appraisal of Quantitative Research”).

2.3.2 Need for Transparency

In addition to having sufficient clarity about how the steps of the research process were executed in terms of both the quantitative and the qualitative components, mixed methods researchers need to also have transparency about mixed methods considerations. Such considerations include the timing of the phases, relative priority given to the various datasets, and the nature of the integration. Clear descriptions of how these steps have been executed allow the reader to evaluate the appropriateness and implications of choices made. The key to demonstrating rigor in mixed methods research is in providing the reader with a clear audit trail and well-considered and justified rationales for the decisions made throughout the research process (Lavelle et al. 2013).

2.3.3 Need for Mixed Methods to Be Linked to Research Questions

While the link between research questions and methodology/methods is important in all research, in mixed methods studies, it is essential to demonstrate the need to employ a mixed methods approach rather than a pure quantitative or qualitative design. There should be a clear and logical flow from the research questions to the data collection and interpretation of findings.

2.3.4 Need to Be Explicit About the Nature of the Mixed Methods Design Employed

Although mixed methods research can certainly incorporate elements of creativity in research design, a number of typologies exist that provide an overview of the most common designs (Creswell and Plano Clark 2011, 2018). These typologies extend beyond providing a framework for data collection and also explicate key mixed methods characteristics such as study purpose, integration timing, allocation of priority, and level of interaction (Halcomb and Hickman 2015).

2.3.5 Need for a Rationale for the Use of Mixed Methods Research

The use of mixed methods should be a deliberate choice to add value to the research above that which could be achieved by a single method study (Creswell and Plano Clark 2011; Scammon et al. 2013). Therefore, in order to allow the reader to understand what the researcher was trying to achieve by mixing methods, the rationale for the design choice should be clearly articulated. Within the mixed methods literature, there has been a significant discussion about the range of rationales for using mixed methods (Greene et al. 1989; Bryman 2006a; Wisdom et al. 2012; Halcomb and Hickman 2015). Where possible this consistent terminology should be used to reduce confusion and promote mutual understanding.

2.3.6 Need for Integration

A frequent criticism of mixed methods research is the absence of integration between the quantitative and qualitative strands of a mixed methods study (O’Cathain et al. 2008; Andrew and Halcomb 2009). This is often seen when the quantitative and qualitative components are reported separately and there is little attempt to explore the richness that could result from the linking of the two datasets (Bryman 2014). Others argue that without integration, the study does not meet the criteria of mixed methods research (Andrew and Halcomb 2009). While, in some cases, some data may be reported separately to meet journal requirements or to report a specific aspect of the dataset, there should be some integration and recognition of papers across a series (see, e.g., Ashley et al. 2018a, b, in press-a, in press-b). There is growing interest in the literature around specific aspects of integration (Bryman 2006a; Andrew et al. 2008, 2011; Zhang and Creswell 2013; Halcomb and Hickman 2015). This growing discourse can help researchers to appreciate the range of strategies available to combine the quantitative and qualitative strands of their mixed methods research to better answer the research question.

3 Conclusion and Future Directions

From the complexity of the quality considerations outlined in this chapter, it is apparent that rigorous quality appraisal of mixed methods research requires specific tools focused on the specific considerations of mixed methods research. While appraisal must incorporate both qualitative and quantitative elements, it must also encompass the characteristics of transparency of decision-making, integration, and

yield that characterize mixed methods research. Given the heterogeneity of mixed methods research and the diversity of researchers employing this methodology, it is unlikely that a single tool will be developed to critically appraise all mixed methods studies. Additionally, some frameworks that have been proposed to date are very lengthy and complex, making appraisal unnecessarily time-consuming for the reviewer. Care must be taken to avoid the assumption that the use of mixed methods makes a study more rigorous. Understanding the considerations identified in this chapter will help the reader to make critical decisions about the quality of mixed methods research and its utility to inform and guide practice.

As mixed methods continue to grow in popularity in the health sciences, it is important that health services and health professional researchers seek agreement about ways of defining and measuring quality in the health sciences. Additionally, researchers embarking on mixed methods research in the health sciences should consider aspects of quality when designing and implementing their research. Embedding quality considerations is vital to ensure that mixed methods research is robust and adds to the body of knowledge informing health policy, education, and practice.

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Section II

Innovative Research Methods in Health Social Sciences



Innovative Research Methods in Health Social Sciences: An Introduction

61

Pranee Liamputtong

Contents

1	Introduction	1072
2	Innovative/Creative Research Methods	1073
3	The Innovative Researcher	1074
4	About the Innovative Research Methods in Health Social Sciences Section	1075
4.1	Theoretical Lens	1075
4.2	Arts-Based and Visual Methods	1076
4.3	The Body and Embodiment Research	1080
4.4	Digital Methods	1082
4.5	Textual (Plus Visual) Methods of Inquiry	1085
5	Conclusion and Future Directions	1087
	References	1088

Abstract

Innovative, or creative research, methods have become increasingly popular in the last few decades. In this chapter, I will include several salient issues on which chapters in the section on “Innovative Research Methods in Health Social Sciences” can be situated. First, I discuss some ideas about innovative and creative methods. This is followed with the notion of those who practice innovative methods: the innovative researcher. I will then bring readers through a number of innovative and creative methods that researchers have adopted in their research. These include the theoretical lens, arts-based and visual research methods, the body and embodiment research, digital methods, and textual (plus visual) methods of inquiry. As an innovative researcher, our choice of innovative methods primarily depends on the questions we pose; the people who are involved; our moral, ethical, and methodological competence as researchers; and the sociocultural environment of

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1071

the research. As we are living in the world that continue to change, it is likely that health and social science researchers will continue to experiment with their creative methods in order to ensure the success of their research. I anticipate that in the future, we will see even more creative methods that researchers will bring forth.

Keywords

Innovative methods · Creative research methods · The innovative researcher · Arts-based research · Visual research · The body · Embodiment research · Digital methods · Textual method of inquiry

1 Introduction

Research differs in the ways in which it is conducted and in the products that it yields. What one needs to research in a situation must be appropriate for the circumstances one addresses and the aims one attempts to achieve. (Eisner 2008, p. 4)

This section presents “new era” in research in the health and social sciences (Sinner et al. 2006). It encourages creative ways that researchers can adopt to access the experiential knowledge of research participants (as well as of their own). Innovative, or creative research, methods have become increasingly popular in the last few decades. They were created and promoted within the USA and the UK, but have now been widely adopted by researchers in other parts of the globe (Gwyther and Possamai-Inesedy 2009).

In 2005, Yvonna Lincoln and Norman Denzin (2005, p. 1116) point out that the current moment in research was “the methodological contested present.” Even the next moment, they argue, will still be “methodological contested” moment as “struggle and contestation” will continue. Indeed, “we are in the new age where . . . new experimental works will become more common” (Denzin and Lincoln 2005, p. 26). In this new age, we have witnessed more creative forms of research bubbled up in health and social sciences. Many of these are included in this section.

As a researcher, Elliot Eisner (2008, p. 5) suggests knowledge, or our understanding of the world, can come in many ways. He contends that knowledge is “not always reducible to language.” Knowledge also “comes in different forms,” and “the forms of its creation differ.” This is also what Norman Denzin (2010, p. 425) has advocated. He encourages health and social science researchers to embrace “methodological diversity.” This is because it will bring “new ways of knowing” which will lead to “new knowledge” (Simons and McCormack 2007).

Within the fractured world in which we are now living, I contend that there are many situations where no conventional method (constructivist, positivist, or mixed methods) will work and can be alienating for some individuals. It is essential that health and social science researchers adopt unconventional alternative approaches (Liamputtong 2007). Indeed, many researchers have increasingly realized the value of more creative inquiries in working with marginalized groups (Gillies and Robinson 2012; Baker et al. 2015). Research that involves children, for example, traditional research methods such as questionnaires, in-depth interviews, or focus

groups may be problematic. Creative methods that treat children as research participants instead of research objects will allow children to play an important role in the research. These creative methods also allow researchers to gain a deeper insight into the understanding and experiences of children (Angell and Angell 2013).

Increasingly too, there have been many health and social science researchers who believe in the social justice value and attempt to change the social conditions of people and communities (Mertens et al. 2009; Denzin 2015; Bryant 2016; Denzin 2017). This is precisely what Denzin (2010) has encouraged researchers who are situated within the “moral and methodological community” to do. This has resulted in the development of innovative and creative approaches in many parts of the globe. These creative approaches are also in expansion. In this section, a number of innovative and creative ways that researchers have utilized in their research is presented.

In this chapter, I will include several salient issues on which chapters in the Innovative research methods in health social sciences section can be situated. First, I discuss some ideas about innovative and creative methods. This is followed with the notion of those who practice innovative methods: the innovative researcher. I will then bring readers through a number of innovative and creative methods that researchers have adopted in their research.

2 Innovative/Creative Research Methods

Innovative or creative research methods here refer to methods which are not situated neatly within the traditional research methods. Taylor and Coffey (2008, p. 8) suggest that innovative methods include “the creation of new designs, concepts and ways doing things.” However, Rose Wiles et al. (2011, p. 588) contend that innovative methods are not necessarily restricted to “the creation of new methods.” They can also refer to “advances or developments of ‘tried and tested’ research methods.” Often, innovative methods are created in an attempt to ameliorate some facet of the research practice which may not work properly (Wiles et al. 2011).

Innovation has been classified into three main areas: new designs or methods, new concepts, and new ways of doing research (Taylor and Coffey 2008; Xenitidou and Gilbert 2009). New designs or methods include data collection and analysis methods as well as representation of research. New concepts embrace frameworks and methodological concepts. New ways of doing research refer to “new applications” as well as “crossing disciplines” (Xenitidou and Gilbert 2009, p. 6). In their report, Maria Xenitidou and Nigel Gilbert (2009, p. 7) define innovative research practices as “those which involve technological innovation, cross disciplinary boundaries and/or extend existing methodologies and methods.”

Some researchers refer to innovative methods as “creative” research methods (Kara 2015; Bryant 2016). Creative methods entail “imagination” (Wilson 2010; Bryant 2016). Imagination is “transformative ways” that researchers perceive and practice their research (Bryant 2016). For Les Back (2012), imaginative methods can widen the sociological imagination of the researchers. They can also help in the pursuit to democratize the research process. Indeed, Caroline Ellis and Art Bochner

(2008) argue that in planning for research, imagination is as crucial as the rigor if researchers wish to produce ethical research. Nick Wilson (2010, p. 368) tells us that imagination “thrives at the edge of things, between the gaps.” For health and social science researchers, this imagination helps to open up creative ways of conducting research that is departed from the traditional ways of doing research. As readers will see, contributors in this section have used their imagination to create innovative and creative methods that they adopted in their research.

In their research with children in a Scottish radiology department, Sandra Mathers et al. (2010) used “graffiti walls” as their creative research method as a means for the children to tell their own stories. Large sheets of paper were painted with “a breeze block pattern” to make it similar to a wall. A cartoon “worm” that invited the children with a phrase “Please use our graffiti wall” was used as starter graffiti because it would help the children to feel more relaxed about adding their own graffiti. Marker pens and crayons were supplied. The graffiti walls were on display for 7 days. The graffiti wall was not supervised and hence the children felt free to post anything on the wall. However, the content was checked daily to ensure that no offensive material was posted. All sheets were photographed at the end of this stage before storage. Mathers and colleagues contend that graffiti walls allowed the children to be able to express their thoughts and experiences. Although the method did not yield a large amount of information (reflecting the nature of graffiti), it was acceptable to the children, and they did participate in the activity.

Innovative research methods have also been coined by Sharlene Hesse-Biber and Patricia Leavy (2006) as “emerging research methods.” These emergent research methods, according to Hesse-Biber and Leavy (2006, p. xi), are “the logical conclusion to paradigm shifts, major developments in theory, and new conceptions of knowledge and the knowledge-building process.” Often, emergent methods are invented to examine research questions that orthodox research methods may not be able to sufficiently address. Theoretical paradigm shifts in the health and social sciences have allowed innovative methods to be developed and this has also resulted in the achievement of new theoretical perspectives within the disciplines. In order to cultivate rich new meanings, emergent methods alter traditional ways of knowing. Emergent methods demand researchers engage “at the border” of conventional methods. Often, we need to operate from a multidisciplinary or interdisciplinary ground (Hesse-Biber and Leavy 2006). According to Hesse-Biber and Leavy (2006), emerging methods can be seen as “hybrid” because often they are borrowed and adapted from different disciplines to generate new tools, or reshape existing tools in order to answer new and often complex questions. Emergent methods can be both qualitative and quantitative methods, or a combination of both approaches, as illustrated in chapters in this section.

3 The Innovative Researcher

I contend that the innovative researcher is an individual who Norman Denzin and Yvonna Lincoln (2005, p. 4) have referred to as the “bricoleur” or “quilt maker.” Denzin and Lincoln suggest that a bricoleur “makes do by ‘adapting the bricoles of

the world.” Bricoles are “the odds and ends, the bits left over” (Harper 1987, p. 74). Thus, the bricoleur is “a Jack of all trades, a kind of professional do-it-yourself” (Lévi-Strauss 1966, p. 17). Denzin and Lincoln contend that there are various types of bricoleurs: interpretive, narrative, theoretical, methodological, and political (p. 4). The result of bricoleur’s method, what they coin as “the solution (bricolage)” is “an [emergent] construction that changes and takes new forms as the bricoleur adds different tools, methods, and techniques of representation and interpretation to the puzzle” (p. 4). Innovative researchers are energized by their curiosity and creativity (Jones and Leavy 2014).

As a quilt maker, the innovative researchers deploy “the aesthetic and material tools” of their discipline, using whatever methods, strategies, and research materials which are accessible to them (Becker 1998, p. 2). As Cary Nelson et al. (1992) contend, what researchers choose as their research practices are depended on the question that is asked and the research context. It also depends on “what the researcher can do in that setting” (Denzin and Lincoln 2005, p. 4). Thus, if the researchers have to initiate or construct new tools, as a quilt maker must do, they will do so (Denzin and Lincoln 2005). In essence, the innovative researchers are what Alasuutari (2007, p. 513) refers to as the “up-to-date, well-informed” researchers who make use of creative methods in their research. For example, nowadays, the availability of mobile phones means that most participants would already have the tools that they need (Phillips 2014). Hence, innovative researchers have made use of the mobile phone as a tool for research, including mobile interviews (see also ► Chaps. 80, “Cell Phone Survey,” and ► 81, “Phone Surveys: Introductions and Response Rates”).

4 About the Innovative Research Methods in Health Social Sciences Section

The section is loosely organized into two main parts. Part one includes some theoretical aspects which are relevant to creative methods that are discussed in the section. Part two embraces a number of innovative and creative research methods that the innovative researchers (the bricoleurs, the quilt makers) have used to answers their research questions (solve their puzzles). I will discuss them in turn in the following sections.

4.1 Theoretical Lens

Two chapters deserve to be treated as the theoretical lens on which chapters that follow are based. Viv Burr, Angela McGrane, and Nigel King introduce the personal construct psychology (PCP) theory developed by George Kelly that innovative researchers can adopt in their creative methods in ► Chap. 62, “Personal Construct Qualitative Methods.” PCP was developed in clinical psychological practice and has now cultivated various techniques that allow individual to gain insight into their own

perceptions and experiences. Within the research context, PCP methods allow research participants to articulate their own experiences and behavior, as well as to gain insight into their own constructions of the world. PCP methods can be viewed as “participant-led” methods. In this chapter, the authors contend that PCP methods offer many values to the qualitative researcher: “They have the advantage of being highly flexible and can be adapted for use in a wide variety of research topics and settings, providing opportunities for qualitative researchers to create innovative ways of researching.”

In ► [Chap. 63, “Mind Maps in Qualitative Research,”](#) basing on the visual approach, Johannes Wheeldon and Mauri Ahlberg write about mind maps that qualitative researchers can adopt in their research. Mind maps, the authors tell us, are valuable tools for researchers because they provide “a mean to address researcher bias and ensure data is collected in ways that privilege participant experience.” Minds map refers to “diagrams used to represent words, ideas, and other concepts arranged around a central word or idea.” They are more flexible than other types of maps and present ideas in a number of ways. Mind mapping is built on the idea that individuals learn in different ways and think using a combination of words, images, and graphics. Wheeldon and Ahlberg contend that visually oriented approaches such as mind maps can assist researchers to plan their research, collect and analyze data, as well as to present their research findings.

4.2 Arts-Based and Visual Methods

Arts-based research is an emergent, appealing, and expanding terrain (Chilton and Leavy [2014](#)). According to Shaun McNiff ([2008](#), p. 29), arts-based research refers to “the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies.” It became to be known between the 1970s and the 1990s, and has now been adopted by many innovative researchers. Arts-based research embraces the assumptions of “the creative arts” in health and social science research. Chilton and Leavy ([2014](#), p. 403) contend that “the partnership between artistic forms of expression and the scientific process integrates science and art to create new synergies and launch fresh perspectives.”

Arts-based research, as Suzanne Thomas ([2001](#), p. 274) writes, possesses “the power to provoke, to inspire, to spark the emotions, to awaken visions and imagining, and to transport others to new worlds.” The arts can assist researchers as they attempt to “portray lives” and light up “untold stories” (Coles and Knowles [2001](#), p. 211; Chilton and Leavy [2014](#), p. 403). Through the arts, we can reach people’s “inner life” through their “stories, metaphors, and symbols, which are recognised as both real and valuable” (Chilton and Leavy [2014](#), p. 403).

Norman Denzin ([2000](#), p. 261) argues that arts-based research is essentially “a radical ethical aesthetic.” Tom Barone ([2001](#), p. 26) suggests that arts-based research methods are valuable for “recasting the contents of experience into a form with the potential for challenging (sometimes deeply held) beliefs and values.” Thus, arts-

based research methods have also become “socially responsible, politically activist, and locally useful research methodologies” (Finley 2005, p. 681).

The arts-based inquiry is situated within a tradition of participatory action research (PAR) in the health and social sciences (Higginbottom and Liamputtong 2015). Researchers adopting this line of inquiry call for a “reinterpretation of the methods” as well as its ethics concerning human social research (Finley 2005, p. 682). They attempt to develop inquiry involving action-oriented processes that provide benefits to the local community where the research is undertaken. Arts-based research, Susan Finley (2005, p. 686) maintains, is carried out to “advance human understanding.” Primarily, arts-based researchers attempt to “make the best use of their hybrid, boundary-crossing approaches to the inquiry to bring about culturally situated, political aesthetics that are responsive to social dilemmas.”

In ► Chap. 64, “Creative Insight Method Through Arts-Based Research,” Jane Edwards suggests that arts-based research (ABR) “represents a way of using the arts to facilitate and enhance processes within research.” ABR embraces “creating works” that health and social science researchers have adopted and these include poetry, narrative fiction, plays, painting, drawing, or song writing. This is in line with what Patricia Leavy (2015) has recently identified as arts-based research: poetry, narrative inquiry, music, dance, performance, and visual arts. Arts-based research offers researchers “boundless possibilities for inventiveness, discovery, and creativity” (Viega 2016, p. 3).

In the last few decades, researchers in the health social sciences have started to embrace the use of visual research so that their understanding of the human condition can be enhanced (Harper 2012; Rose 2012; Andriansen 2012; Gubrium et al. 2015; Kolar et al. 2015; Leavy 2015). There are a wide variety of visual forms that are available to researchers. Each of these visual forms can result in different ways of knowing. Thus far, we have witnessed visual forms such as photographs, drawings, cartoons, graffiti, maps, diagrams, films, video, signs, and symbols have been adopted in research in the health and social sciences (Weber 2008). Most often, however, health and social science researchers use visual methods together with some form of interviewing.

Images speak louder than words (Harper 2002, 2012) and there is a saying that “a picture is worth a thousand words” (see ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method”). A picture can be captured instantly at a glance, but those thousand words would need time to read or to listen to (Weber 2008). Eisner (1995, p. 1) too argues that images provide an “all-at-once-ness” which help to explain things that would be difficult to capture through words and numbers. Images can also invoke social justice actions. Weber (2008, p. 47) invites us to visualize this:

Take, for example, the powerful photograph taken by Nick Ut during the Vietnam War of an obviously terrified young Vietnamese girl running naked down a street to flee a napalm fire bomb. It may have done more to galvanise the antiwar movement in the West than all the scholarly papers on the horrors of war.

The use of visual images as a data collection tools in research can assist health social science researchers in many ways. Weber (2008) suggests a few. Images can assist us to capture knowledge that is hidden, elusive, or hard-to-put-into-words which would be ignored or remain hidden without the use of visual forms. Photographs, for example, can greatly invoke “information, affect and reflection” (Rose 2007, p. 238) that written texts may not be able to do. Similarly, drawing and painting can grasp “capacity, range, and emotions” which are not easily produced in words alone (Russell and Diaz 2013, p. 2). Images can assist researchers to pay attention to things in different ways. Ordinary things can become extraordinary with the use of images. This can make us embrace new ways of doing things. Often, images can invoke new research questions and inspire the research design (Weber 2008).

Authors of chapters in Part 2 in the Innovative research methods section make use of visual images in their research. In Understanding health through a different lens: Photovoice method, Michelle Teti, Wilson Majee, Nancy Cheak-Zamora, and Anna Maurer-Batjer tell us that in health research and practice, visual methods are common tools. Public health researchers have appreciated the values of photography as a means “to understand health issues from the perspectives of those living with health challenges, inform health interventions, and engage community members in identifying and solving health problems.” In their chapter, however, Teti and colleagues write about the application of the Photovoice method to HIV/AIDS and Autism Spectrum Disorder research and practice. Within community-based participatory action research (PAR), the method of Photovoice has emerged as an innovative means of working with marginalized people and in cross-cultural research. Photovoice method allows individuals to record and reflect the concerns and needs of their community via taking photographs. It also promotes critical discussion about important issues through the dialogue about photographs they have taken. Their concerns may reach policy-makers through public forums and the display of their photographs. By using a camera to record their concerns and needs, it permits individuals who rarely have contact with those who make decisions over their lives, to make their voices heard (Wang 1999; Wang and Burris 1994, 1997; Wang et al. 2004; Lopez et al. 2005a, b; Castleden et al. 2008; Rhodes et al. 2008; Hergenrather et al. 2009; Teti et al. 2012; Sanon et al. 2014; Switzer et al. 2015; Maratos et al. 2016; Rose et al. 2016).

In ► Chap. 66, “IMAGINE: A Card-Based Discussion Method,” Ulrike Felt, Simone Schumann, and Claudia Schwarz-Plaschg write about a card-based discussion method, what they also coin as the IMAGINE methodology, that they employed in their qualitative research and engagement in the Austrian context. This method extends the focus group method commonly adopted in qualitative inquiry in that several prepared cards are used to create some imaginations among the participants. They tell us that by providing different sets of cards for participants to work with, the method can “stimulate and support the process of developing imaginations with regard to emerging technoscientific and other complex social issues.” In an interaction with other participants in the group, the method can “enhance the capacity to gradually assemble the ‘building blocks’ that are used to assess an issue and construct a position.” The core interest of this card-based discussion method is “to

investigate how people analyze and relate to specific matters of concern in the present and to their potential futures, i.e., how they think a specific part of ‘the world’ works and how they imagine it might or should work in the future.”

E. Anne Marshall, in ► [Chap. 67, “Timeline Drawing Methods,”](#) discusses the value of timeline drawing method in qualitative research. Timelines refer to “visual representations of particular and selected events or ‘times’ in a person’s life” (see also Guenette and Marshall 2009; Adriansen 2012; Jackson 2012; Kolar et al. 2015; Rimkeviciene et al. 2016). A timeline is coined by Lynda Berends (2011, p. 2) as “visual depiction of a life history, where events are displayed in chronological order.” Timelines, depending on the research focus, can cover a participant’s lifetime, a particular number of months or years. Timelines can be created by a participant or a researcher, or collaboratively. They can also be constructed at different times in the research process. The authors suggest that timelining “adds a visual representation related to the experience that can anchor the interview and help focus the participant on key elements.” The method is especially suitable for sensitive and complex research or when the oral language expression of the participants is limited due to a number of situations: “Timelining can provide participants with a way to engage their stories deeply and even help to create new meanings and understandings.”

► [Chapter 68, “Semistructured Life History Calendar Method”](#) is written by Ingrid A. Nelson on semistructured life history calendar as a method in health social science research. The Life History Calendar (LHC) has been used as one key method for gathering quantitative life course studies (see Belli et al. 2009; Kendig et al. 2014; Morelli et al. 2016; Vanhoutte and Nazroo 2016). In LHC method, researchers utilize “a preprinted matrix, with time cues running horizontally across the page and topic cues running vertically down the page, to help respondents piece together their past.” However, traditional LHC is highly structured. It does not allow researchers to obtain in-depth understanding about why or how the life story of the participants is unfolded as it is. Due to the need for comprehensive contextual data in qualitative life course research, Nelson created a semistructured adaptation of the LHC. Nelson contends that “this methodological innovation incorporates research participants’ attitudes and aspirations, interpretations and explanations of life transitions, and major events that would not be captured in standardized event histories.” The semistructured LHC method attains “nuanced longitudinal narratives” by marrying “the characteristic detail across multiple domains of the traditional LHC with in-depth narrative.”

The last chapter in this section, ► [Chap. 69, “Calendar and Time Diary Methods,”](#) is written by Ana Lucía Córdova Cazar and Robert F. Belli on time use research, focusing on calendar and time diary methods which have been shown to be particularly effective for assessing human well-being. Time use research methods are composed of both time diaries and life histories or event history calendars. It has been widely accepted that time use research allows researchers to understand human behavior and its intrinsic relationship with individual and social well-being. It has attracted the interest of researchers from many disciplines including the health and social sciences. The authors argue that “although these methods forego the

standardization of question wording (the most prevalent approach in traditional survey interviewing), they are nevertheless able to produce reliable and valid responses, while also encouraging conversational flexibility that assists respondents to remember and correctly report the interrelationships among past events.”

4.3 The Body and Embodiment Research

Corporeal realities, or embodiment, has become a site of attention among feminist and postmodern researchers (Gonzalez-Arnal et al. 2012; Lennon 2014). This has resulted in the advancement of creative methods that can be used to elicit the knowledge of the corporeality (the body) within the social sciences (Hesse-Biber and Leavy 2006; Gray and Kontos 2015). According to Hesse-Biber and Leavy (2006, p. xix), “all social actors are embodied actors – our experience, vision, and standpoint are embodied. We know and experience social reality from our embodied standpoints within the society.” The embodiment is embraced by Elizabeth Grosz (1994) as the “lived” or “inscribed” body. The lived body symbolizes experiential knowledge that is connected with the physicality of an individual (Hesse-Biber and Leavy 2006; Tarr and Thomas 2011). It is through the lived body that meanings are brought about (Grosz 1994; Liamputtong and Rumbold 2008; Tarr and Thomas 2011; Gonzalez-Arnal et al. 2012; Lennon 2014). As a researcher, we can attain crucial knowledge by the lived body of the research participants. At the same time, we can also access this important knowledge through our own body (Hesse-Biber and Leavy 2006; Todres 2007; Gonzalez-Arnal et al. 2012; Lennon 2014).

In their conversation about how to obtain knowledge about the identities of individuals, David Gaunlett and Peter Holzwarth (2006, p. 8) contend that “we need research which is able to get a full sense of how people think about their own lives and identities, and what influences them and what tools they use in that thinking, because those things are the building blocks of social change.” This has prompted many embodiment researchers to invent creative methods that can allow them to do so. Some of these are included in this section.

The body mapping method, as Bronwyne Coetzee, Rizwana Roomaney, Nicola, Willis, and Ashraf Kagee write in ► Chap. 70, “Body Mapping in Research,” is a “research tool that prioritizes the body as a way of exploring knowledge and understanding experience.” Body mapping is a creative method that really grabs the imagination of research participants (Brett-MacLean 2009; Orchard et al. 2014; de Jager et al. 2016; Ebersöhn et al. 2016). In the body mapping method, life-size body drawings are drawn (or painted) to visually portray “aspects of people’s lives, their bodies and the world they inhabit” (see also Gastaldo et al. 2012). The method has also been coined by researchers in the human and social sciences as “body map storytelling” because the meaning of a body map can only be fully understood by the story and experience as told by the individual who creates the body map.

Anna Bagnoni, in ► Chap. 71, “Self-portraits and Maps as a Window on Participants’ Worlds,” presents two creative methods in her research regarding identities. One is the body mapping and the other the self-portrait method, which she created

herself in her doctoral study. Within this method, the body is located at the center as in the body mapping method. She provides the participants with a blank sheet of paper, colored felt-tips, and pens. She then invites the participants to show who they are at the present moment in their lives. They are also asked to add anything that is important to them at that moment. In her study, the self-portrait method was invented as “a creative input to support in particular those who might not feel too comfortable with words when asked about personal and subjective issues, and might feel reassured by writing, drawing or doodling as alternative forms of self-expression.”

Creative research methods that incorporate a bodily experience also include walking and talking together with the research participants (Brown and Durrheim 2009; Carpiano 2009; Evans and Jones 2011; Garcia et al. 2012; Begeron et al. 2014; Holton and Riley 2014). As Alexandra King and Jessica Woodroffe write in ► [Chap. 72, “Walking Interviews”](#), walking interviews involve researchers and participants talking while walking together. According to King and Woodroffe, “as a shared corporeal or bodily experience, the physical act of walking alongside someone shapes the research encounter, aiding the development of an intersubjective understanding of the physiological particularities of a respondent’s lifeworld.” Walking interviews are “a valuable means of deepening understandings of lived experiences in particular places.” Walking interviews generate “rich, detailed and multi-sensory data.” For health research, the authors contend, walking interviews permit researchers to “engage with the nature and meaning of bodily experiences including physical well-being, illness, ageing or disability, and to explore the ways in which these experiences are interwoven with the places in which people live and the meanings they have for their lives.”

Similarly, in ► [Chap. 73, “Participant-Guided Mobile Methods,”](#) Karen Block, Lisa Gibbs, and Colin MacDougall discuss what they coin as the participant-guided mobile method. Participant-guided mobile methods blend a participant-led guided tour with an in-depth interviewing method (see also Finlay and Bowman 2016). The authors suggest that the tour can occur “on foot or using a vehicle and can even be virtual, investigating participants’ online worlds or using technologies such as Google Earth or Google Maps to explore otherwise less accessible places.” With the participant-guided mobile method, researchers are able to access “multiple types of data simultaneously; adding contextual, observational, and potentially also visual data to interviews conducted in a naturalistic setting.”

Voice, according to Hesse-Biber and Leavy (2006, p. xxv), is also a part of the corporeal realities because voice occurs “in a cultural context, in relation to self, and in relation to others.” Voice is hinged on a mutual form of expectation. Voice, when it is expressed in certain ways, such as the digital storytelling method, allows individual’s stories to be heard. In ► [Chap. 74, “Digital Storytelling Method,”](#) Brenda Gladstone and Elaine Stasiulis present the digital storytelling method that they employed in their research with young people in Canada. Digital stories refer to “short (2–3 min) videos using first-person voice-over narration synthesized with visual images created in situ or sourced from the storyteller’s personal archive.” The method permits the first person narrative; the participants have an opportunity to write and use their own voice to tell their own story. This is indeed where the power

of the method lies. The method is also situated within the “emergence of arts-based health research” and is adopted widely in community-based participatory research, public health and health promotion research and practice (see Alexandra 2015; Otañez and Guerrero 2015).

4.4 Digital Methods

Digital methods refer to the application of “online and digital technologies” that researchers utilize to gather and analyze research data (Snee et al. 2016, p. 1). Globally, the digital has become a significant part of our daily life and researchers within the health and social sciences have embraced it as part of their creative research methods (Turney and Pocknee 2005; Liamputtong 2006; Dillman 2007; Hewson 2014; Rogers 2013; Synnot et al. 2014; Halfpenny and Proctor 2015; Iacono et al. 2016). We have witnessed a number of research projects that make use of digital methods in recent time. Annette Markham (2004, p. 95) writes:

[T]he internet provides new tools for conducting research, new venues for social research and new means for understanding the way social realities get constructed and reproduced through discursive behaviours.

Digital methods have many advantages over more conventional research methods. Digital communication can reach a large number of people across different geographical and sociocultural boundaries (Hessler 2006; Cater 2011; Sue and Ritter 2012; Iacono et al. 2016). Chris Mann and Fiona Stewart (2000, p. 80) argue that “the global range of the Internet opens up the possibilities of studying projects which might have seemed impracticable before.” Gillian Dunne (1999), for example, was able to conduct in-depth interviews with gay fathers from different international locations including the UK, New Zealand, Canada, and the USA.

Digital methods provide possibilities to reach a terrain of vulnerable participants, such as people with disabilities, mothers at home with small children, older people, and people from socially marginalized groups such as gays and lesbians, who may not be easily accessed in face-to-face research methods (Mann and Stewart 2002; Elford et al. 2004; Seymour and Lupton 2004; Egan et al. 2006; Liamputtong 2006, 2013; Synnot et al. 2014; see ► Chap. 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool” and ► Chap. 79, “Asynchronous Email Interviewing Method”). These vulnerable individuals can make contact with others from their familiar and physically safe locations. People with disabilities who have access to email and necessary online information can take part in research without having to leave home or be mobile (Seymore and Lupton 2004). Digital methods also permit health and social science researchers a possible vehicle for connecting with people situated within restricted access like schools, hospitals, cult and religious groups, bikers, surfers, punks, and so on.

In social science areas, digital methods provide the possibilities of carrying out research within politically sensitive or dangerous areas (Mann and Stewart 2002).

Due to the anonymity and physical distance, both the researchers and the participants are protected (see Coomber 1997, for example). Some highly sensitive and vulnerable participants, such as political and religious dissidents or human rights activists, will be more likely to participate in online research without excessive risk. Researchers can access censored and politically sensitive information without being physically in the field. People living or working in war zones, or sites of criminal activity, or places where diseases abound can be accessed without needing to combat the danger involved in actually visiting the area. Digital methods also permit researchers to distance themselves physically from research sites. This helps to eliminate the likelihood of suspicion that might alienate some participants.

In this section, several innovative methods that situated within the digital methods are included. In ► [Chap. 75, “Netnography: Researching Online Populations,”](#) Stephanie Jong writes about netography in health social sciences. Netnography, according to Jong, can be seen “as a means of researching online communities in the same manner that anthropologists seek to understand the cultures, norms and practices of face-to-face communities, by observing, and/or participating in communications on publically available online forums” (see also Nelson and Otnes 2005; Bowler 2010; Kozinets 2010, 2015). In this chapter, Jong explores the transition of netnography, a consumer marketing method, to the field of health social science research using the example of her study related to fitness communities on social networking sites (SNSs).

In the past two decades, we have witnessed a growth in the area of online survey methodology (see Evans and Mathur 2005; Wright 2005; Lieberman 2008; Murray et al. 2009; Greenlaw and Brown-Welty 2009; Sue and Ritter 2012; Kramer et al. 2014). As the general population becomes increasingly made up of “digital natives” (Kramer et al. 2014), web surveys will become more prominent, particularly in the health domain (Riper et al. 2011; Kramer et al. 2014). In ► [Chap. 76, “Web-Based Survey Methodology,”](#) Wright contends that an online survey method is a valuable tool for health researchers. Many health researchers have employed online surveys to access various population groups, including consumers, patients, caregivers, health care professionals, online support community participants, and policy-makers in the health care system. In his chapter, Wright provides salient issues relevant to the use of online surveys to reach a number of stakeholders in the health care system, including patients, caregivers, and health care providers.

Recently, we have witnessed an increase use of blogs in research (see Wakeford and Cohen 2008; Chenail 2011; McCosker and Darcy 2013; Harricharan and Bhopal 2014; Saiki and Cloyes 2014; Wilson et al. 2015; Genoe et al. 2016). In ► [Chap. 77, “Blogs in Social Research,”](#) Nicholas Hookway and Helen Snee write about blogs in social research. Blogs, accordingly to the authors, are “the quintessential early twenty-first century text” that made “the boundary between private and public” obscured. Blogs refer to “interactive and multimedia, converging text, image, video, GIFS and other types of media into one space.” For health social science researchers who are interested in the everyday life of individuals, blogs can offer rich and first-person textual accounts. Hookway and Snee contend that “embracing new confessional technologies like blogs can provide a powerful addition to the

qualitative researcher's toolkit and enable innovative research into the nature of contemporary selves, identities and relationships."

Another digital method that has become popular in the health science is an online interviewing method, either synchronous or asynchronous. As we have witnessed, electronic mail (email) has been used widely as an effective tool of communication (Meho 2006; Burns 2010; Brondani et al. 2011; Cook 2012; Ratislavová and Ratislav 2014; Bowden and Galindo-Gonzalez 2015). In *Synchronous Text-Based Instant Messaging: Online Interviewing Tool*, Gemma Pearce, Cecilie Thøgersen-Ntoumani, and Joan Duda discuss online interviewing using synchronous text-based instant messaging. The synchronous text-based online interviewing method is "a method of interviewing participants online using an instant messaging service to type to each other (text-based) at the same time in a conversational style (synchronous)." Using an Instant Messaging service to conduct interviews is unique in its "ability to carry out a synchronous discussion with the participant." This method is essentially useful for situations where face-to-face or telephone interviews are problematic.

Similar to the previous chapter, in *Asynchronous Email Interviewing Method*, Mario Brondani and Rodrigo Mariño contend that "in the era of multimedia and *at-finger-tips* convenient information, electronic communication can provide answers to research inquiries in a timely manner." This is particularly so when the researcher does not need to meet face-to-face with the research participants or have difficulties in meeting them personally. In this chapter, the authors discuss the use of email interviews and offer readers nine steps for conducting an email interview which would help readers to get the most out of the method.

Digital methods also include the use of mobile or cell phone via wireless web devices in data collection (Casey and Turnbull 2011; Hesse-Biber 2011). Mobile devices including cell phones and smart phones have become an intrinsic element of peoples' daily lives (Casey and Turnbull 2011). As such, they have become a means for health and social science researchers to conduct their research. In ► [Chap. 80, "Cell Phone Survey,"](#) Lilian A. Ghandour, Ghinwa El Hayek, and Abba Mehio Sibai write about cell phone survey research. In this chapter, the authors tell us that the increase in global cell phones usage has eroded traditional data collection means, particularly landline surveys. This has led to the development of novel survey methods and designs. They contend that using a single landline frame survey is problematic. As a result, researchers have invented methods that can integrate the cell phone and landline frames, and conducted "dual frame" surveys using either overlapping or nonoverlapping modes of integration. The authors also point out that cell phones are likely to become "an inevitable mode" for researchers to collect health survey data particularly when existing barriers are reduced.

The last chapter in this part, ► [Chap. 81, "Phone Surveys: Introductions and Response Rates,"](#) is also on phone survey but its focus is on how to increase response rates. Jessica Broome contends that although telephone surveys have been declined due to the increase of web surveys, phone surveys "are far from becoming extinct." Due to the limited Internet access in some groups such as older and lower income people, a telephone is still a preferred method when researchers need to reach broad cross-sections of a population (Lepkowski et al. 2008; Tomlinson et al. 2009;

DeRenzi et al. 2011; Dillon 2012; Bradley et al. 2012; van Heerden et al. 2014). This is particularly so in the health research arena. Several large-scale surveys such as the Behavior Risk Factor Surveillance System (BRFS), California Health Interview Survey (CHIS), and the Canadian Community Health Survey (CCHS) still rely heavily on telephone surveys. But a phone survey has its own challenges (see O'Toole et al. 2008; Haberer et al. 2010). A critical aspect of phone surveys is the introduction as this can impact greatly on the response rates of the surveys. Broome contends that "introductions that are effective at convincing sample members to participate can help to improve shrinking response rates in this mode." In this chapter, Broome provides some creative suggestions for effective interviewer training that can increase the response rates in phone surveys.

4.5 Textual (Plus Visual) Methods of Inquiry

Researchers in the health and social sciences have used writing as a means for collecting research data (Warkentin 2002; Hesse-Biber and Leavy 2006). Writing can act "as a process of discovery" for both the researchers and the researched (Hesse-Biber and Leavy 2006, p. xxvii). As researchers have to create a new means to provide answers to their particular research questions, the new method that focuses on writing and the textual data has emerged (Hesse-Biber and Leavy 2006). Some of these new ways of collecting research data are included in this section.

Marsha Quinlan, in *Freelisting Method*, writes about the freelisting method which has been adopted widely in the social sciences and has recently become more popular in health research (see Ryan et al. 2000; Fiks et al. 2011; Huang 2014; Auriemma et al. 2015; Jonas et al. 2015) (► Chap. 82, "The Freelisting Method"). A freelist is "a mental inventory of items an individual thinks of within a given category." In a research using the freelisting method, research participants are asked to list things (or persons) that they see to be part of a realm (for example, "ways to avoid HIV," "breakfast foods," "reasons to fear hospitals," or "treatments for a cough") in whatever order they can think off. The lists that the participants come up with can "tap into local knowledge and its variation" of the community under investigation. In health social science, Quinlan tells us that the freelisting method is "ideal if one wants to find the most culturally salient knowledge (e.g., cut treatment, mosquito control), attitudes towards, or associations with, an issue or topic (e.g., obesity, vaccinations, violence), or different ways locals do something (e.g., prepare a medicine or a food, decide on healthcare)." Data generated from the freelist method "allows the researcher to discover the relative salience of items across all respondents within a given domain." The freelisting method is mostly done through written data but it can also be oral and via the Internet as well.

In ► Chap. 83, "Solicited Diary Methods," Christine Milligan and Ruth Bartlett write about the diary method they used in their research. The diary has been adopted as a research method in health social science research (see Galvin 2005; Jacelon and Imperio 2005; Alaszewski 2006; Hyers et al. 2006; Gills and Liamputtong 2009; Nezlek 2012). There are two types of diary method: solicited and unsolicited

(personal diaries). The solicited diary method is written for the purpose of research in minds (Elliott 1997; Jacelon and Imperio 2005; Nezelek 2012). The participants explicitly write their diaries as data for the researcher with a full knowledge that their writing will be used in research and will be read and interpreted by another person (Jacelon and Imperio 2005). Through diaries, the researcher can collect data about the day-to-day events of participants, and then further investigate those events in subsequent interviews. Diaries offer researchers hints about the events which are important for the participants as well as their attitudes toward those events (Jacelon and Imperio 2005). People may record their feelings, experiences, observations, and thoughts about a particular aspect of their lives in a diary (Hesse-Biber and Leavy 2006; Nezelek 2012). The method can provide researchers with in-depth understandings of, for example, the experience of living with HIV/AIDS, dealing with daily discrimination, and caring for a child with disabilities and so on. Hence, diary method can be an invaluable vehicle to gather information from some sensitive issues and with hidden and hard-to-reach populations. However, it is noted too that researchers may also combine textual data with visual and/or digital data. As Milligan and Bartlett suggest, a diary can be recorded digitally and visually.

In ► Chap. 84, “Teddy Diaries: Exploring Social Topics Through Socially Saturated Data,” Marit Halder and Randi Wærdahl tell us about a creative method they used in their research on family lives; what they coin as teddy diaries. After the school reform in Norway in 1997, Teddy bears and teddy diaries were introduced as “a pedagogical device to ease the transition between a student’s family and the first year of school.” Each new school class receives a teddy bear who will visit every child’s home in turn. The teddy bear carries a diary where the bear’s experiences in the child’s home are recorded. During the first school year, the teddy will visit each student a number of times. The children, or the children together with their parents, write a diary that describes activities that the bear is involved with the child and the family on a given day. The child and the family can decide on topics that they believe worth mentioning to teachers, classmates, and other families as these people would share the diary entries that the child and the parents have written. Teddy diaries, according to Halder and Wærdahl, “can be read as an exchange of normative everyday standards between different homes, and between home and the school public.” Arguing from a research perspective, they contend that “researcher effect is relatively low, but the impact of the social, cultural and contextual on the data is very high. What we actually learn from these diaries are topics that a researcher would not necessarily ask about, yet that convey highly saturated information about norms and values and those that are socially accepted. What is exchanged and reinforced by the evaluation of others becomes the most interesting feature of the material.” They conclude that “teddy diaries, as naturally occurring data, are a good source of knowledge about the norms, values and ideals in the social context we wish to examine.”

Another textual method that is rather creative is the story completion method (SC). Virginia Bruan, Victoria Clarke, Nikki Hayfield, Naomi Moller, and Irmgard Tischner, in *Qualitative Story Completion Method*, introduce “a novel technique” which provides “exciting potential” to researchers, particularly qualitative researchers (► Chap. 85, “Qualitative Story Completion: A Method with Exciting

Promise"). In this method, a researcher writes "the start of a story", referred to as "a story 'stem' or 'cue'." Often, it will be an opening sentence (or two). The participants are then invited to continue or complete the story. The authors tell us that SC was "originally developed as a form of projective test, for use by psychiatrists and clinical psychologists, to assess the personality and psychopathology of clients." The authors also contend that this method holds much potential for researchers, as they have demonstrated vividly in this chapter.

5 Conclusion and Future Directions

In this chapter, I have presented readers with a number of innovative and creative research methods that researchers in the health and social sciences have used in their research. Sue Wilkinson (2004, pp. 271–272) contends that "a method is an interpretation." When researchers choose a method for their research, their decision is not only based on an epistemological and theoretical reason, but also moral and ethical considerations. The contributors to this section have shown this when they adopt innovative or unusual methods in their research. They are attuned to "the epistemological commitments and value assumptions they make" when proposing or using a particular creative research method. The contributors also use their ways of knowing and creativity to forge new ways or revamp old methods in order to meet the needs of their research environment and the people that involved. Research methods, as Hesse-Biber and Leavy (2006, p. xxx) tell us, are "not fixed entities." Often, research methods are "fluid." They "can bend and be combined to create tools for newly emerging issues and to unearth previously subjugated knowledge." This can also be attested in chapters in this section.

As for any research method, I am in no way suggesting that all of these innovative methods will suit all research projects and contexts, nor that these creative methods are better than the orthodox methods. I am not suggesting either that these innovative methods are without challenges. Indeed, each method presents some epistemological, practical and ethical challenges to the researchers and the research participants and these can vary according to different socio-political-cultural situations. We as innovative researchers must bear this in mind in adopting these methods. And of course, there are other creative and innovative methods that health and social science researchers may wish to experiment with that I have not been able to include in this section. There is always a space limit in a book. I would suggest that we do our own experiment with our creative methods and then document it so that other researchers may be able to see and follow our steps. This is the only way we can make our innovative research known by others and hope that someone will adopt it in their future research.

As an innovative researcher, our choice of innovative methods primarily depends on the questions we pose; the people who are involved; our moral, ethical, and methodological competence as researchers; and the sociocultural environment of the research. As we are living in the world that continue to change, it is likely that health and social science researchers will continue to experiment with their creative methods in order to ensure the success of their research. I anticipate that in the future, we will see even more creative methods that researchers will bring forth. It is really exciting indeed.

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Personal Construct Qualitative Methods

62

Viv Burr, Angela McGrane, and Nigel King

Contents

1	Introduction	1096
2	A Constructivist Epistemology	1096
3	Constructs and Construing	1097
4	PCP Methods: Key Features	1098
5	Eliciting and Using Constructs in Research	1099
5.1	Eliciting Constructs in an Interview: Cross-Cultural Perceptions	1099
5.2	The Triadic Method of Construct Elicitation: The Self in Relationship	1100
5.3	Interviewing Using Elicited Constructs: Footwear and Women's Identities	1101
5.4	Laddering: Reflective Practice in Social Work	1102
5.5	Analysis of Constructs	1105
6	The Pictor Technique: Experiences of Care	1105
6.1	The Pictor Technique: Procedures	1106
6.2	Analysis of Pictor Charts	1107
7	The Self-characterization Sketch: Work Placements and Students' Perceptions of Self	1109
7.1	Analysis of the Self-characterization Sketch	1109
8	Reflecting on the Use of PCP Methods	1110
9	Conclusion and Future Directions	1111
	References	1111

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1095

Abstract

In this chapter, we examine a number of research methods arising from personal construct psychology (PCP). Although its techniques are often relatively unfamiliar to qualitative researchers, we show how PCP provides opportunities to extend and enrich the predominant methods currently used by them. PCP adopts a constructivist epistemology and offers a number of techniques for enabling people to gain insight into their own and others' constructions and perceptions. We outline several of these techniques in this chapter, illustrating them through examples of our own research and providing some guidelines for data analysis.

Keywords

Construct elicitation · Constructivism · Construing · Laddering · Personal construct psychology · Pictor · Self-characterization sketch

1 Introduction

Although social scientists often have some familiarity with personal construct psychology (PCP), many are not aware of the range of qualitative methods it offers. PCP originated in clinical psychological practice with the work of George Kelly (1955) and has since developed a number of techniques for enabling people to gain insight into their own and others' thinking which have been successfully adapted and applied in organizational, educational, and health and social care research. The Repertory Grid is probably the most familiar and widely used PCP method, but it has been principally used as a quantitative technique. Although the potential of this and other PCP methods for qualitative research is now being acknowledged (see Fransella 2005), PCP methods are still relatively unknown to qualitative researchers.

In this chapter, we will examine a number of research methods arising from PCP and argue that they provide opportunities to extend and enrich the predominant methods currently used by qualitative researchers. We illustrate these methods through examples of our own research and provide some guidelines for data analysis.

2 A Constructivist Epistemology

PCP can be thought of as one of a number of approaches referred to as “contextual constructionism” (Madill et al. 2000), where reality is seen as actively constructed through our interpretative processes. Since there are many different ways of interpreting the world characteristic of different societies, cultures, groups, and individuals, there are multiple constructed realities and alternative perspectives on the world. Kelly (1955) referred to this as “constructive alternativism.” Contextual constructionism differs from, and can be thought of as lying somewhere between, realism (the idea of a single, objectively defined reality) and radical constructionism (the idea that our constructions of the world are constructed without reference to any presumed external “reality”).

Like other constructivist theories, PCP argues that one account of reality cannot be regarded as any more “accurate” than another, locating it as a relativist approach. Relativism is the idea that points of view have no absolute truth or validity in themselves; they can only have relative, subjective value, so some accounts may be more useful or facilitative than others for the person. In this emphasis upon individual experience and knowledge as a useful construction, PCP is philosophically grounded in both pragmatism and phenomenology (Butt 2008). Pragmatism emphasizes the utility rather than the truthfulness or accuracy of people’s knowledge, and PCP is phenomenological since it is concerned with the world as it is perceived by the person, the “phenomena” that present themselves to consciousness.

At the heart of PCP is the idea that people actively construct themselves and their psychosocial world in the course of daily life, using their subjective experience and its personal and social meanings. PCP sees people as conducting themselves and making choices according to these meanings and thus stands in contrast to theories that regard the person’s qualities or behavior as determined by internal or external forces. It also rejects causality as an explanatory concept, since human beings are seen as having choice and agency. PCP theory and methods are, therefore, epistemologically compatible with approaches that take seriously subjective experience and/or that challenge deterministic or essentialist models of the person.

3 Constructs and Construing

Kelly was working as a clinical psychologist in the USA in the 1930s and developed PCP as an alternative to the mainstream psychologies of the day, behaviorism and psychoanalysis, with which he became dissatisfied. Rather than life events causing people to be traumatized, Kelly felt that it is our interpretation of events, the meaning they hold for us rather than the events themselves, that can be problematic. How people perceive or “construe” events is seen as key to understanding them.

Kelly argued that people construe the world in their own idiosyncratic way, using a system of meaning that each individual builds for themselves. This “construct system” is like a lens through which we perceive the world, giving it a particular appearance and significance. A person’s construct system is thought of as a set of bipolar dimensions (“constructs”) that each take the form of a contrast, such as “vulnerable vs. resilient” or “independent vs. sociable,” and the person constantly uses these to interpret their experience. However, we are often not consciously aware of our construing; it is our taken-for-granted way of seeing things.

Construing, therefore, frames and gives meaning to our experience, powerfully influencing our interactions and relationships. For example, when one nurse meets a new patient for the first time, they may be (nonconsciously) asking “are they going to be compliant or refuse their medication?” whereas another may be asking “will I be able to help, or will I feel frustrated?” The nature of their relationship and interaction with the patient is inevitably shaped by this construing; the two nurses may be expected to have somewhat different perceptions of and interactions with the same patient. In PCP terms, if we want to understand a person, we must gain some insight into their construing.

But our many constructs do not exist independently of each other; they are linked together in a system. They are arranged hierarchically, with relatively concrete and mundane constructs, used in relation to quite narrow aspects of life, at the bottom of the hierarchy and more abstract constructs relating to our overarching values and beliefs at the top. For example, lower level constructs for a person might include “rhythmic vs. melodic” (in relation to music) or “talkative vs. reserved” (in relation to people). A construct higher up their system, to which the lower ones will be related, might be “stimulating vs. dull” as this could apply to both music and people. This might in turn be subsumed under an even higher-order (or “superordinate”) construct such as “life-enhancing vs. life-limiting.” This relationship between constructs means that they have meaning implications for each other. In the hypothetical example above, the person may be drawn to “talkative” people as “talkative” to some extent also implies “life-enhancing” for them. This hierarchical organization of constructs is explicitly used in the method of “laddering” which we explore later.

4 PCP Methods: Key Features

Kelly devised methods to enable him and his clients to gain insight into their construing, and other PCP clinicians and researchers have since developed a considerable number of further techniques for this purpose. Such methods may be used within a PCP theoretical framework but can also be adopted in a wider range of approaches that sit at the intersection between constructivism and phenomenology, where subjective experience and perceptions are the focus.

The aim in PCP psychotherapy is to enable the client to articulate and inspect their own construing in order to allow them to understand and overcome their psychological difficulties. Similarly, in the research context, PCP methods focus on enabling people to reflect upon their own experience and conduct and gain insight into their own construing. In PCP therapy, it is important to gain an in-depth understanding of the client’s worldview, seeing and describing the world in their terms rather than as seen by the therapist. Similarly, PCP research privileges the “voice” of participants. The PCP researcher is careful to describe events in terms used by participants themselves; in giving verbal and written labels to their constructs, care is taken to adopt the words and terms used by the participant. The participant’s perspective always remains the priority, ensuring that the interpretative process remains in their control rather than being taken over by the researcher. PCP methods, therefore, explicitly “democratize” the relationship between client and practitioner, researcher and researched. Whereas other methods of analysis, such as IPA (Smith and Osborn 2003), rely principally upon the researcher’s interpretation of an interview transcript some time after the interview, a characteristic of PCP methods is the greater time spent during data gathering in agreeing construct labels and their meanings with the participant.

In this sense, PCP methods can be described as “participant-led.” Participant-led techniques such as photo-elicitation and audio diaries are often adopted in difficult or sensitive areas of research so that participants from marginalized or vulnerable

groups are given greater agency than they would in a conventional interview (Liamputtong 2007; Pink 2007; Johnson 2011; Sargeant and Gross 2011; see also “Understanding Health Through a Different Lens: Photovoice Method” and “Digital Storytelling Method”). But PCP methods have three potential additional benefits. Firstly, although they are intrinsically participant-led, they are used in collaboration with the researcher. This avoids participant worries about “doing it right” when asked to produce the required material unaided. Secondly, PCP methods are less reliant on the verbal fluency of participants than methods where people are asked to explain the meaning of what they have produced; PCP methods can be particularly effective in researching experiences that are hard for participants to access and articulate, as it focuses on concrete examples from their experience. This focus on the concrete can enable participants to overcome the difficulties of expressing abstract ideas. Thirdly, PCP methods tend to be very efficient; in our experience, participants are generally able to carry out the exercises in a relatively short time while still producing rich data. Furthermore, with some participant groups it can be difficult to avoid socially desirable but readily available responses, for example, where practitioners are keenly aware of what is regarded as “best practice” in their field. Using concrete examples provides a means of accessing accounts reaching beyond socially desirable or common-sense responses since they avoid asking participants direct questions about what they feel is important.

In the remainder of this chapter, we will illustrate several methods derived from PCP, chosen to indicate something of the range of issues that they may be used to address. Some of these methods (the various forms of construct elicitation) are explicitly designed to identify participants’ bipolar constructs, while others (Pictor and the self-characterization sketch) aim to gain access to the participant’s broader construal of their role in their social world.

5 Eliciting and Using Constructs in Research

There are numerous methods for helping participants to articulate their construing and for gaining access to the bipolar constructs that inform their meaning-making activities. We will first describe how construct elicitation may be used as part of the familiar in-depth interview, describe the commonly used “triadic” method of construct elicitation, and show how “laddering” may be used to help participants to articulate constructs akin to their core values and assumptions.

5.1 Eliciting Constructs in an Interview: Cross-Cultural Perceptions

A common method of data collection in qualitative research is the in-depth interview. However, interviewing requires skill in the effective use of probes and prompts (King and Horrocks 2010). Moreover, where the research topic is psychologically and socially complex, participants can struggle to articulate their experience.

Literature on interviewing about difficult and sensitive topics (e.g., Lee 1993; Liamputtong 2007; Mercer 2008) suggests that it can be time-consuming, requiring the researcher to explore more accessible aspects of experience first, and to use multiple probes to “get below the surface.” But, using a PCP approach to interviewing can help to quickly bring significant issues into focus for discussion.

We will illustrate this through a research study in which we invited participants to compare the perceived characteristics of English and Italian people (Burr et al. 2014a). Small groups of participants in the UK and Italy were interviewed with questions such as “What comes to mind when you think of someone as ‘typically Italian/English’?” and “What do you think Italians/the English imagine when they think of someone as being ‘typically English/Italian’?” We audio-recorded the interviews and also used a simple flip chart to write down the first pole of emerging constructs, such as “passionate and romantic” and “self-contained,” and then asked for contrast poles for these. For example, the English participants suggested that Italians have a “musical, expressive language.” They were then asked “as opposed to what? How are English people by contrast?” and they suggested “loud” and “raucous.” The interviewers then discussed with the group all the responses on the flip chart, clarifying the constructs and, in particular, their contrast poles. Care was taken to use construct labels with which all participants in the group felt comfortable and that they felt represented the range of views expressed. The audio recordings were later used as a check on these constructs. This method enabled us to identify interesting similarities and differences in construing between the two cultures. There was a good degree of shared construing, referred to in PCP as “commonality”; for example, both English and Italian participants used constructs around hospitality, involving a contrast between “giving of oneself” to strangers as opposed to being more “detached,” and around family life with the contrast of being family-oriented as opposed to being more independent of family. But subtle differences in the constructs used by the two cultures were often very informative. While the English participants saw English people as not very hospitable or “giving” of themselves, the Italian participants construed this English reserve as “valuing privacy”; the English participants envied the Italian culture in its family focus, but the Italians felt their own close family involvement may cast them as “Mummy’s boys” in the eyes of others.

Constructs previously elicited, often using the “triadic” method, can also be used as the starting point for an in-depth interview. Before going on to provide an example of this, we will therefore describe the triadic method of construct elicitation using a research example.

5.2 The Triadic Method of Construct Elicitation: The Self in Relationship

This popular method typically entails the comparison of things, people, or events, referred to as “elements,” in groups of three (“triads”) and asking the participant to think of any way in which two are similar and different from the third (Kelly’s

definition of a construct). A pool of elements is first developed. Where the topic under investigation concerns our construing of people and relationships, these elements would typically consist of people known to the individual. The number of elements used is not important, but there should be enough to enable a range of comparisons to be made. They might be asked to compare, for example, their mother, their best friend, and their brother. They may answer “Two of these people are outgoing but the other is shy,” so the bipolar construct elicited here is “outgoing – shy.” Comparison of different triads of elements would produce further constructs, such as “tidy – chaotic” or “thorough – hurried.”

Inspection of the list of constructs obtained in this way can itself provide insight into the individual’s worldview and promote useful discussion with them. Butt et al. (1997) used this method to examine people’s sense of self in their relationships with others. Participants were asked to think of themselves in relationship with a variety of others in their lives, and all of these different “selves” constituted the elements in the construct elicitation process. They were asked to compare these selves in triads, producing a range of constructs related to their sense of self. An example of the constructs produced by one participant, “Katherine,” can be seen in Fig. 1, and we will comment on these constructs in the section on construct analysis.

5.3 Interviewing Using Elicited Constructs: Footwear and Women’s Identities

Using elicited constructs as the starting point for an interview can enable the researcher to focus on and probe significant issues. The interview can be used for refining the elicited constructs with the participant, and the interview transcript can additionally be analyzed in the usual way, with the possibility of using some constructs as a-priori codes. Burr et al. (2014b) show how this method was used to explore four women’s identities using shoes. Pictures of a wide range of footwear

feel defensive.....not defensive
 feel uncomfortable.....feel comfortable
 I’m guarded.....I’m open
 feel disinterested.....feel concerned
 unsure.....relaxed
 wouldn’t share my feelings.....would share my feelings
 want to protect myself.....feel comfortable
 feel resentful.....don’t feel resentful
 unstimulated.....stimulated
 feel vulnerable.....don’t feel vulnerable
 distrust them.....trust them

Fig. 1 Katherine’s Constructs

formed the pool of elements. Triads of images were presented to the women and they were asked to compare these in terms of the “personality” the shoes might be said to have, or the kind of woman who might wear them. Elicited constructs included a number relating to sexuality and “sexiness,” issues that were clearly of importance to the women; but these were subtly different for each participant. For one participant, the contrast to “sexy” was “old-fashioned” whereas another contrasted “overtly sexual” with “toned down sexual.” The women were then interviewed, probing into the meaning of the elicited constructs and producing rich insights into their sense of self.

5.4 Laddering: Reflective Practice in Social Work

Burr et al. (2016) used a laddering exercise with undergraduate social work students to enable them to reflect upon the more value-laden constructs that might be said to lie towards the “top” of their construct hierarchy.

Social work practitioners are expected to reflect on their practice, to gain insight into their reactions to clients, their own decision-making, and the assumptions and values that drive these. Reflexive thinking is, therefore, explicitly addressed in the education of social work students. Students are often required to write reflective assignments to demonstrate the insights they have gained.

However, reflecting upon one’s assumptions and beliefs is not necessarily easy to do, since these are often “ground” rather than “figure” for us; we may need assistance to render them “visible” to us and therefore available for inspection. With some participant groups, it can also be difficult to avoid socially desirable responses, for example, where practitioners are keenly aware of what is regarded as “best practice” in their field, and this is arguably the case with social work students. A structured exercise can help participants to articulate underlying values and assumptions, and can help avoid the tendency to simply report socially desirable ideas. First described by Hinkle (1965), laddering takes previously elicited constructs and uses these to explore the person’s superordinate constructs, those that say something about the values and taken-for-granted assumptions that inform their conduct. It is especially helpful when the participant has difficulty in articulating their abstract values and beliefs, or explaining the reasons for their behavior.

One of the person’s previously elicited constructs is selected and written down, preferably one that is relatively “subordinate” or “concrete,” for example, “reserved vs. chatty.” They are then asked to say which pole of the construct they would prefer to see themselves at and to say why. Their response is written above that pole of the construct. They are asked what the contrast would be and their response is written above the other pole. In this example, they might say they would prefer to be “chatty” because chatty people are “socially adept” as opposed to being “hard to relate to.” These two responses now effectively constitute another, more abstract, construct, and the two constructs constitute the first two “rungs” of a ladder (see

Fig. 2 Two “rungs” of a ladder**Fig. 3** Jenny’s constructs

senior level – entry level
 caring – cold
 highly strung – calm
 harsh – warm
 client centred – business centred
 detached – mindful of clients
 immature – mature
 complacent – super keen

Fig. 2). The same process is applied to the new construct and so on until the person cannot meaningfully “ascend” any further.

However, it is important not to think of the identification of constructs as an end in itself. The process of reflecting in-depth upon one’s construing is likely to be more important than the specific outcomes of the exercises. Therefore, in our research, we were relatively unconcerned with exploring students’ construct systems, focusing instead on the effectiveness of their self-reflection.

The students were asked to think of a number of people whose social work practice they were familiar with and these, including themselves, formed the “elements” of a construct elicitation task using the triadic method as described earlier. In making their comparisons, they were asked to focus on the behavior and practice of the individuals. Jenny’s constructs (see Fig. 3) are an example.

We then chose relatively “concrete” or subordinate constructs from each student’s list for laddering as described above. For example, Jenny’s construct “senior level – entry level” appears very concrete and would be a better candidate for laddering than “client centered – business centered,” which is more abstract. The students each produced between two and four ladders, using different constructs as the starting point each time.

The ladders sometimes produced counter-intuitive results. For example, Fig. 4 shows Alice’s ladder, which prompted a good deal of self-reflection.

The laddering began with Alice’s construct “too nose vs. not nose enough.” The concept of “nosiness” usually carries pejorative meanings, and it seemed that Alice was unsure of just how “nosey” a social worker ought to be. But in completing this ladder, it was clear that Alice was reflecting on her social work values. As she

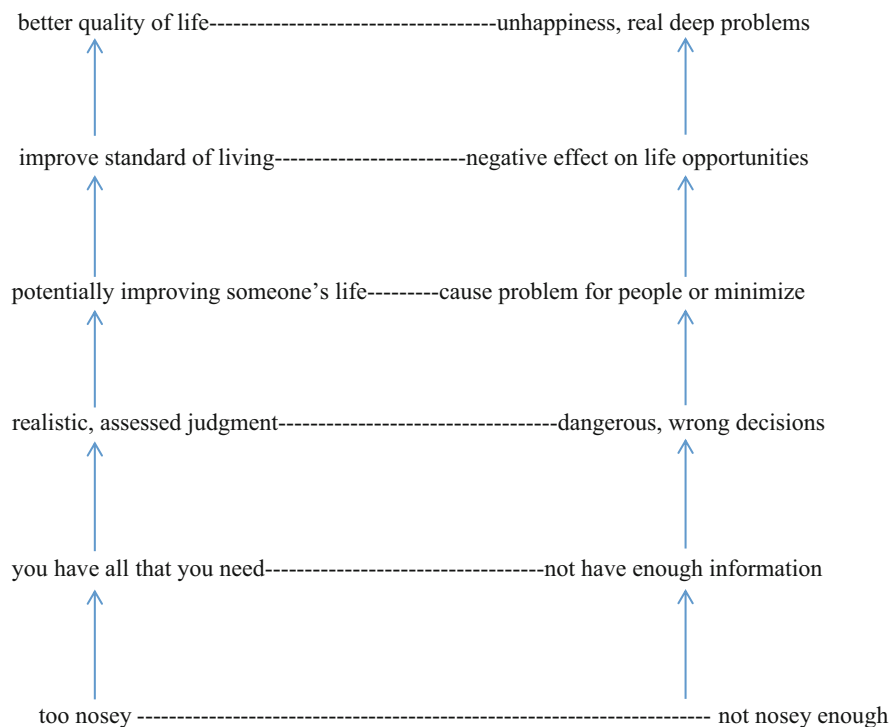


Fig. 4 Alice's ladder

proceeded with the exercise, she reflected on the implications of these two kinds of behavior and concluded that it was important for a social worker to be highly inquisitive about a service user's situation in order to realistically assess the problem and, ultimately, give the service user a better quality of life.

Laddering is generally accepted as a technique that allows researchers to see the organization of a person's construct system, helping us to access their superordinate constructs. However, Butt (2007) and Bell (2014) have challenged this. They suggest that construct systems are not so neatly organized, and that conceptualizing them in this hierarchical way leads to confusion about what laddering can achieve. They acknowledge that laddering sometimes does lead "upwards" to constructs that are more abstract and value-laden than those we began the exercise with, as was clearly the case for some of our participants. But, sometimes it does not, and we can end up "going round in circles," with the constructs elicited later looking similar to those we started with. This happened with some of our participants. Nevertheless, what laddering does is to help us explore the implications of some of our construing. It gives us insight into how our constructs are related to each other, and in so doing frequently offers us food for reflective thought. So "going round in circles" is not necessarily a problem- interesting issues may nevertheless be revealed in the process.

5.5 Analysis of Constructs

As with other qualitative methods, analysis of the data from construct elicitation is largely interpretative. One might look for “themes” in the constructs as one would with interview data, the difference being that the researcher need not examine large amounts of material to find issues of significance (Braun and Clark 2006; see also “Qualitative Story Completion Method”). A quick inspection of Katherine’s constructs (Fig. 1) suggests a theme of wariness and self-protection. Her constructs around feeling defensive, guarded and distrustful, and feeling vulnerable and needing to protect herself suggest a relational world fraught with threat and potential danger. This is certainly not all that can be said about Katherine as a person; the construct elicitation exercise produces a vivid picture of one aspect of her sense of self. But we might assume that such construing would be important in understanding the nature of Katherine’s interactions and relationships with others.

Although the focus of construct elicitation is usually idiographic, it is also possible to examine the construing of a wider sample of participants. In our research on women’s identities, we went on to elicit constructs about shoes with over 20 further women using the same images. We then performed a content analysis on these constructs, identifying clusters of constructs that appeared to hold common significance for the women. They provided 215 constructs in total. Although many of these appeared to be idiosyncratic, 162 constructs were judged to show some commonality and were coded into categories. These categories included femininity, elegance, sexuality, boring, exhibitionism, conformity, and individuality. But, as in the interview stage of the research, it was an examination of the contrast poles of the constructs that was particularly informative. For example, the contrasts to “boring” supplied by the women suggested a preference for fun and frivolity, glamor and excitement, creativity and expressiveness, interest and vibrancy. The data also suggested a tension for women between expressing themselves as individuals and being seen as attention-seeking and exhibitionist. Likewise, it suggested a desire to be “sexy” but sexiness also often involved less welcome descriptions such as “tarty” and “slutty.” The analysis, therefore, identified some interesting tensions and fault-lines in the women’s identities.

6 The Pictor Technique: Experiences of Care

Pictor is a visual method based on a technique used in PCP family therapy (Hargreaves 1979). The client writes the names of family members on arrow-shaped cards and lays them out in a way that illustrates the perceived nature of relationships between them. Ross et al. (2005) developed this for research purposes in a study of collaborative working between health and social care professionals. In their previous, traditional semistructured interviews, some participants had presented a rather sanitized and idealized version of collaboration that appeared to reflect the rhetoric of their professional training rather than lived experience. Borrowing from Hargreaves, Ross et al. (2005) tried asking participants to represent, with a name on a

cardboard arrow, each of those involved in a case and to place them on a large sheet of paper, using features such as direction and proximity of arrows to indicate significant aspects of roles and relationships. They found that the “charts” thus produced served as very effective facilitators to detailed discussion of the case, encouraging a focus on the concrete and specific rather than the abstract and generalized. A further advantage was that it helped both interviewer and interviewee to keep in mind a wide range of individuals and services involved in a case; in conventional interviews this had proved hard to do and consequently there was a tendency to concentrate just on a few main players

With some refinements to the procedure, discussed below, and the discovery of arrow-shaped sticky “Post-it” notes that were more convenient to work with, this technique was developed into Pictor by King and colleagues at Huddersfield (King et al. 2013). We have used Pictor in several studies looking at the complex collaborative working that occurs for people with life-limiting illnesses (e.g., King et al. 2010, 2017; Noble et al. 2014). Hardy et al. (2012) extended the use of the technique to patients and their primary lay carers, to explore how they saw themselves in a network of care and support; and Elliott et al. (in preparation) have used it with parents of children with Autism-Spectrum Disorders. We have found Pictor successful in eliciting rich and detailed accounts, and in the great majority of cases, participants – whether professionals or lay people – have responded very positively to it. While our research has been in health and social care settings, the technique can be used in any circumstances where people need to collaborate to achieve a goal or to provide some kind of support to someone, for example in business, education, and the criminal justice system.

6.1 The Pictor Technique: Procedures

Turning now to the procedure for using the technique, the participant is asked to think of a particular “case” of collaborative working. If they are a patient or client, this would be their own case. They would then be asked to think of all those involved in the case and write a pseudonym or other identifier on a sticky arrow for each person/agency. The arrows are normally available in three different colors, and participants are told they can use the colors to indicate something if they wish. They then lay out the arrows on a large sheet of paper in a way that helps them tell their story of the case. Participants are told that features such as the direction of the arrows, the spaces between them, and the way they are grouped can be used to indicate particular aspects of roles and relationships, but there is no “right” way to do it – above all, they should carry out the task in the manner that best enables them to describe the case. The researcher may leave the room while they are completing the chart, but sometimes participants prefer them to stay – often because they are concerned about getting it “wrong.” While there is a risk of the interviewer influencing chart construction, there are often benefits in hearing (and recording) participants vocalizing their reasons for placing arrows as they do. Once the chart is complete, it is used in an interview as the starting point for probing the participant about their

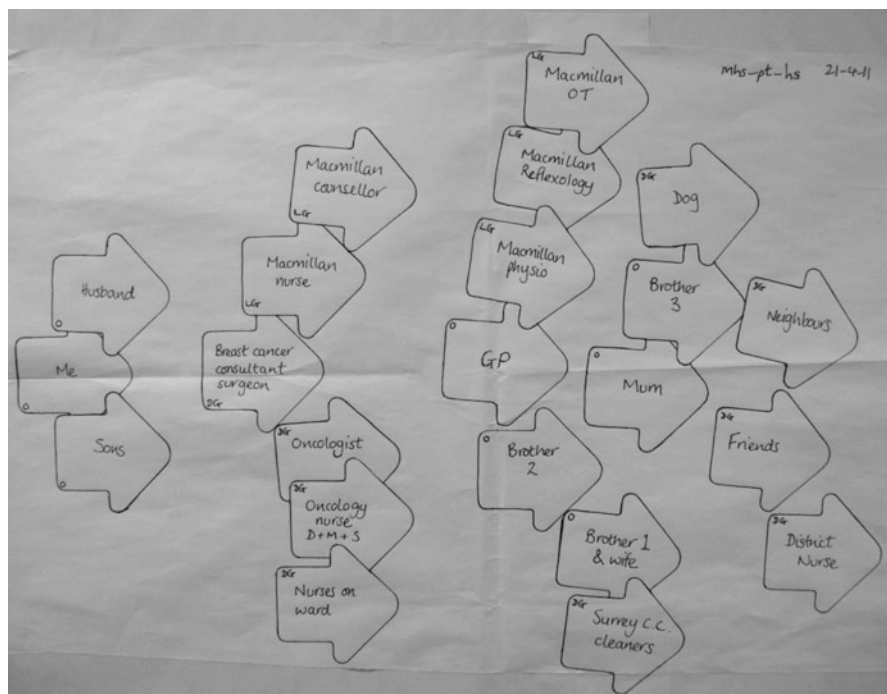


Fig. 5 Example of a Pictor chart

perspective on the story. At the end of the interview, it is best to draw around the arrows, as they can be prone to falling off in transit! If real names are used by participants, they should be anonymized at this point. A good-quality digital photograph of the chart is a simple and practical way to keep a record of it.

Fig. 5 shows a Pictor chart from a study funded by Macmillan Cancer Support, which evaluated an innovative community-based palliative care service in Midhurst, West Sussex. Pictor was used to examine how professionals, patients and carers viewed experiences of care. This chart was created by “Ella,” a woman in her forties with terminal breast cancer.

6.2 Analysis of Pictor Charts

As in the case of other PCP methods, the Pictor chart is examined together with the participant, the arrow patterns noted by the researcher serving as interview prompts.

The way in which Ella laid out the arrows for her chart is very clearly structured. She presents herself on the left of the chart, overlapped by her husband and sons, with four distinct rows of arrows moving away from her. It is important when discussing the chart with a participant not to make assumptions about what particular positions might mean. In this case, Ella was quite explicit that proximity reflects how

important particular individuals or agencies were in her care. For example, pointing to the “Macmillan Counsellor” arrow she says:

...and [name], that's [name]; I'd say [name] is very important as well. These come down like that [pointing along the line]. I'd say that's probably my main support team, they're the ones that I go to most.

Immediately after this, she points to the second line of arrows and says:

And then I'd probably put my GP [places arrow] who's got more involved lately. See, I don't see these [Macmillan OT, Reflexology, Physio] a lot but when I have met them they've been important.

It is interesting to note that her family members are either presented as if part of a unit with her (husband and sons), or are in the second or third “lines” of support. From her comments, this clearly reflects their less central roles than the (literally) closest family members. For instance, she says “. . .my Mum bless her, Mum tries and my other brother [brother 3].” She explains her placing of the district nurses in the furthest position in line four rather apologetically, but with the clear intent of indicating a degree of disappointment:

I'm not sure if I'm doing the district nursing justice, I don't know, it's just they're probably the ones I feel probably could have been around a bit more.

While we developed Pictor to help elicit rich and detailed interview responses, the Huddersfield team quickly recognized that the charts should be considered as part of the data along with the interview transcripts. They can, for example, help identify key themes in the way a participant construes their situation, such as Ella's perception of a “main team” in contrast to secondary supporters. It may also be valuable to compare features of charts across groups of participants to see whether there are differences that might be meaningful. For example, do carers tend to use the arrows in different ways from patients? Comparisons based on the charts should not be treated as if they were hypothesis tests, of course, but direct the analyst's attention to the relevant transcripts to interrogate these further.

The Pictor technique has, in our view, some clear strengths for constructivist, qualitative research. Most participants engage well with it, reporting that they enjoy doing it; many have described the process as “illuminating” or “surprising,” suggesting it succeeds in bringing to awareness taken-for-granted ways of construing the world. Using the chart in the interview achieves a strong emphasis on concrete examples of lived experience. Also, the chart often appears to help the interview process seem less interrogative to participants; both interviewer and interviewee can focus together on examining the chart. A small proportion of participants struggle to understand the task, so it is a good idea to have an example to show – ideally not on the same topic as the project at hand, to avoid leading the participant. The technique requires space in the interview setting to lay out a large sheet of paper, so improvisation may be necessary!

7 The Self-characterization Sketch: Work Placements and Students' Perceptions of Self

The self-characterization sketch as a method for construct elicitation arose in Kelly's clinical practice and is described in detail by him (Kelly 1955, p. 323). The participant is asked to produce a description of themselves, written in the third person, as if they were "the principal character in a play." They are also asked to write it from the perspective of a friend who knows them intimately and sympathetically. The idea is that this sketch provides an insight into the person's construing of themselves and others. The researcher then inspects the sketch to create a basis for dialogue which can clarify the world view of the writer. In addition to their use in therapeutic work self-characterization sketches (e.g., Fransella and Dalton 2000; Androutsopoulou 2001), they have also been used in education research (e.g., Pope and Denicolo 2001).

In the example presented here, they were used to explore undergraduate students' views of themselves in relation to a work role, looking at how this changes and develops through time and with experience. Joanne, a second year social work undergraduate, was invited to complete a self-characterization sketch imagining herself in a future job. In order to encourage her to explicitly think of her work self, the instructions were adapted from Kelly's original script:

Write a character sketch of yourself as you think of or imagine yourself in a work role, ideally in the type of role you think you would like to take up after graduation. Write just as if you are the principal character in a play. Write it as it might be written by a friend who knows you very intimately and very sympathetically, perhaps better than anyone ever really could know you. Be sure to write it in the third person. For example, start out by saying "Joanne as a social worker is. . ."

7.1 Analysis of the Self-characterization Sketch

Kelly (1955, pp. 330–340) recommends a number of different "readings" of the sketch in order to draw out issues of significance. This is an interpretative process and involves, for example, analyzing how the sketch is organized, identifying themes and pulling out significant words and phrases.

Some initial analysis of Joanne's self-characterization sketch took place before discussing it in depth with her. The aim was to understand how she saw her anticipated role within the world of work she described. "Where did *she* place *herself*?" and "what did *she* see as important?" were key questions for this reading. The first and last sentences of the account can give particular insights, the first sentence setting out the safest and most secure place for the writer to start describing themselves and the final sentence providing a glimpse of the construed future. Joanne started her sketch by saying she had worked hard to achieve her degree and become a social worker, and finished by saying she would like to make a difference within her field of work and these were both useful areas to explore with her.

In imagining herself as a newly qualified social worker, Joanne also said:

...she has done an excellent job of adapting to the job requirements. She demonstrates an ability to manage workload and asks for help if required during supervision. She gets on well with colleagues and supports them during difficult times. Whilst the job hasn't been easy and there has definitely been stressful situations, Joanne has used her initiative to deal with the situation.

From just this short extract, constructs related to her adaptability, being able to manage workload, asking for help, using initiative, getting on well with colleagues, being supportive, finding the job difficult and using her initiative can be seen. These were used in the interview for discussion and further elaboration. These constructs, together with other impressions gained from analysis of the sketch, provided a rich source for discussion with Joanne. For example, would she say that, now, she is someone who asks for help or not? How has her construal of herself in relation to this changed since she started her degree, and how does she think it might change by graduation?

Most participants produce a relatively short self-description. In Joanne's case, the entire sketch was only about 270 words, and yet, used as a basis for the subsequent interview, it provided a rich insight into her anticipations and hopes for herself as a social worker.

8 Reflecting on the Use of PCP Methods

PCP methods may initially be experienced as rather different from conventional qualitative methods. They impose a degree of structure on the interaction between researcher and participant, requiring tasks to be carried out in a certain order, for example eliciting constructs and then laddering them. This may appear restrictive to qualitative researchers, but our experience is that participants actually find this structure helpful. Data gathering with PCP methods tends to have a lively and dynamic feel to it, with participants taking a very active role; they are 'doing something' more than just sitting and answering questions, and often report that they found the experience not only interesting or revealing but also fun.

While recommending PCP methods, we acknowledge that they have challenges and potential drawbacks. They can seem rather game-like to some participants, suggesting that their experiences are being trivialized. This can usually be addressed by taking time to explain why the technique is useful for the particular research project in which they are involved. Another difficulty can be deciding how much to intervene in the process of generating data. For example, when using Pictor to explore collaborative working, Bravington (2011) found that some ways of laying out the arrows tended to produce richer descriptions than others. The researcher might, therefore, decide to reflect this in their guidance to participants, but then too much intervention by the researcher might undermine the essential participant-led nature of PCP methods.

9 Conclusion and Future Directions

We have demonstrated some of the PCP methods that are likely to be of value to the qualitative researcher. They have the advantage of being highly flexible and can be adapted for use in a wide variety of research topics and settings, providing opportunities for qualitative researchers to create innovative ways of researching.

Our experience is that participants find PCP methods engaging and interesting, and that they have a number of advantages compared with more familiar qualitative methods. They are essentially participant-led, enabling participants to remain in control of the research process while benefitting from guidance from the researcher; they enable participants to quickly focus on issues of importance through the use of concrete examples, which is also helpful in topics where participants find it hard to abstract from and articulate their experience. In reflecting upon the data produced, participants produce accounts that are particularly rich and the process often results in the participant gaining a new awareness and insight. They help to avoid common-sense or party-line responses, which is especially useful when exploring sensitive issues. And where appropriate, they can enable the researcher to handle data from larger samples than is usual in qualitative research by searching, say, self-characterization sketches or interview transcripts for construct dimensions rather than performing a thematic analysis.

The principle use of PCP methods in qualitative research has been the exploration of personal experience and selfhood. But, in common with narrative psychology and social constructionism, PCP emphasizes the constructed nature of our psychological and social worlds and there is therefore no reason why PCP methods should not also be used by discourse analysts in researching social constructions. PCP's clinical origin also means that its methods are particularly effective for addressing issues of change, making them particularly appropriate for action research where social or community change is the desired outcome.

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Mind Maps in Qualitative Research

63

Johannes Wheeldon and Mauri Ahlberg

Contents

1	Introduction	1114
2	Background: Mind Maps and Qualitative Research	1115
3	Mind Maps: Theory and Methods	1116
4	Mind Maps and Qualitative Research: Applications and Examples	1117
4.1	Planning Research	1117
4.2	Collecting Data	1118
4.3	Analyzing Data	1118
4.4	Presenting Data	1119
5	Assessing Mind Maps: Value(s), Limitations, and Challenges	1120
6	Mind Maps and Mixed Methods	1123
7	Case Study: Mind Maps: Priming the Pump, Depth, and Detail	1123
8	Mind Maps and Health and Social Sciences	1125
9	Conclusion and Future Directions	1126
	References	1127

Abstract

Traditionally, qualitative data collection has focused on observation, interviews, and document or artifact review. Building on past work on visual approaches in the social sciences, in this chapter we consider the value(s) of mind maps for qualitative research. Mind maps are useful tools for qualitative researchers because they offer a mean to address researcher bias and ensure data are collected in ways that privilege participant experience. Qualitative researchers can benefit from visually oriented approaches to research by using them to assist them to plan

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their research, collect qualitative data, analyze what they have collected, and present findings. Of particular interest in this chapter is how mind maps can offer a graphic and participant-centric means to ground data within theory, assist participants to better frame their experience, and can be used as part of the design and development of additional data collection strategies and mixed methodological approaches. While future applications of mind maps are likely to use technological tools and techniques, there is value in the original approach of putting pen to paper and engaging in a creative and tactile process of outlining ideas and recounting experiences.

Keywords

Mind mapping · Qualitative research · Theory · Constructivism · User generated data collection · Mixed methods

1 Introduction

Qualitative research provides an interpretation of the social world of research participants by concentrating on their “experiences, perspectives, and histories” (Ritchie and Lewis 2003, p. 3; Liamputtong 2017). Prioritizing individualistic accounts of knowledge, experience, and perception, meaning discovered through social interactions privileges the constructed realities of individuals when reporting social science research findings. In addition to more traditional approaches to qualitative research, new approaches have sought to explore how visual approaches can make more evident how an individual constructs, frames, and describe one’s experience (Wheeldon and Faubert 2009).

Although widely used data gathering techniques for human subjects research such as participant observation, interviews, and focus groups are still important (Wolcott 1990), mapping provides a means for participants to personally construct a graphic representation of their experiences (Wheeldon 2010). Focused on precision (Winter 2000) and credibility (Hoepf 1997), qualitative researchers have also begun to acknowledge that the approach chosen by the researcher shapes subsequent research interactions (Feyerabend 1978). These choices mean that the role of the researcher in assigning value to one of what may be many possible meaningful interpretations of the same data must be confronted (Guba and Lincoln 1989).

The trend toward reflexivity (MacBeth 2001) has helped to explicitly outline the role of the researcher in qualitative analysis. To address this concern, researchers often explicitly consider personal and epistemological reflexivity to acknowledge their own possible biases (Willig 2001). Cognizant that the approach chosen by the researcher will shape any interaction between the phenomena studied and the data collected (Feyerabend 1978), qualitative researchers acknowledge the importance of the role they themselves play within their own research (Guba and Lincoln 1989).

New approaches of data collection include vignette responses, subject-operated cameras/videos/sound recordings, focus groups, journaling, and visual life histories (Wheeldon and Faubert 2009). Mind maps offer yet another means. This chapter

explores mind mapping, outlines its key features, and provides practical guidance for employing it in fieldwork, outlining some epistemological, ethical, and practical considerations for researchers. Finally, it canvasses its varied applications for qualitative health research.

Key aims of this chapter are to:

- Provide some background and context to the emergence of the method
- Situate the method within methodological and theoretical approaches
- Provide consideration of the strengths and advantages, weaknesses, and limitation of the method
- Look at its compatibility and use with other methods
- Briefly explore the key issues and practicalities of using the method
- Provide case study examples of mind maps in practice
- Outline areas in which mind maps are used within the health and social sciences

2 Background: Mind Maps and Qualitative Research

Traditionally, qualitative data collection methods include observational methods, in-depth interviews, and group-based approaches, such as focus groups (Liamputtong 2013). Interviews are one of the most common data collection methods in social research (Denzin 2001; Serry and Liamputtong 2017). An interview, which is a verbal exchange between an interviewer and one or more interviewees (Varga-Atkins and O'Brien 2009), can be conducted in a variety of ways. While there are numerous variations of the application of an interview (open or closed questions, in person or over the phone), there is a common understanding about what the data collection approach of “interviewing” generally means across research disciplines. This is not the case when it comes to the data collection approach of using maps.

A major issue complicating knowledge translation regarding visual methods in the natural and social sciences is the different terminology used to describe diagrams (Umoquit et al. 2011). To establish an overarching “umbrella term” that groups the different uses of diagrams in the data collection process, the boundaries of the larger category of graphic communication and where the term diagram fits in must first be clarified. Mind maps are more flexible than other forms of visual approaches (Wheeldon and Ahlberg 2012). Defined as diagrams used to represent words, ideas, and other concepts arranged around a central word or idea (Buzan 1991), mind maps are structurally more flexible than other sorts of maps and present ideas in a variety of ways (Buzan 1974). Figure 1 provides an example.

The re-emergence of visual maps in social science research has occurred at a time when there appears to be a desire to develop data collection methods that are either more explicitly user-generated or which are less influenced by what may be *sui generis* research/participant interactions. For qualitative researchers, they offer a way for researchers to “... search for codes, concepts and categories within the data... based on how the participant(s) frame(d) their experience” (Wheeldon and Faubert 2009, pp. 72–73). Since 1997, maps have been used with increasing

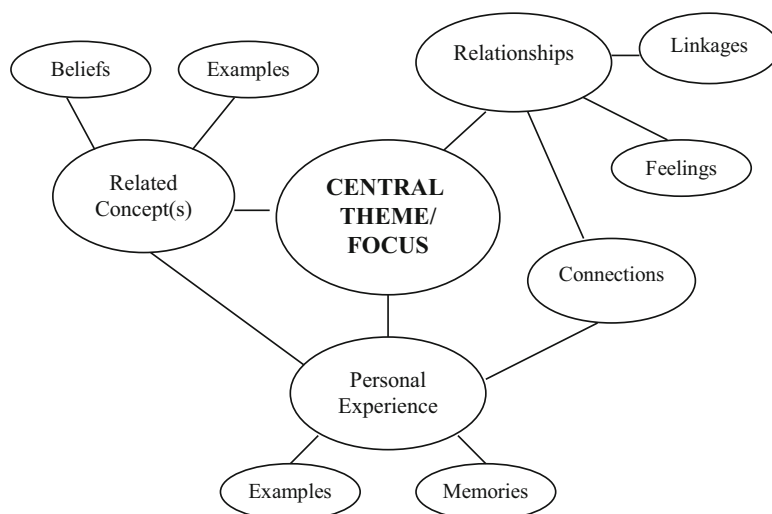


Fig. 1 Constructing a Mind Map (Wheeldon 2010, p. 91)

frequency in fields such as health, education, sociology, and engineering (Nesbit and Adescope 2006).

3 Mind Maps: Theory and Methods

Mind maps are best suited to qualitative research because they can be connected to the theoretical starting place generally associated with qualitative research (Wheeldon and Ahlberg 2012). For those who hold constructivist accounts of knowledge, meaning is assumed to be highly subjective and best understood through social interaction, and personal histories and experiences (Creswell and Plano Clark 2007; see also ► Chap. 7, “Social Constructionism”). As a result, knowledge is inherently localized. Linked concepts can uniquely demonstrate how participants connect their experiences (Daley 2004). Using maps in this way may provide a means to prompt research participants to consider past experience in more depth and detail (Legard et al. 2003).

The theoretical value of mapping is based on the acknowledgment that people learn in different ways and think using a combination of words, graphics, and images. For qualitative researchers, the use of interviews as the sole means of data collection may be relying on psycho-linguistic assumptions about the role of syntax, semantics, and context to guide their construction of meaning (Cassirer 1946). Because people live their lives both in their own head and as part of a social, cultural, and linguistic collective (Habermas 1976), consciousness is both something that people experience on their own and through their interactions with others (Husserl 1970). Because maps offer a unique way for research participants to represent their

experiences, they may provide a means for individuals to think more clearly by avoiding the assumptions built into language (Korzybski 1933). They may provide one strategy to break out of conventional and linguistically limited representations of experience, rehearsed narratives, and canned responses (Hathaway and Atkinson 2003).

4 Mind Maps and Qualitative Research: Applications and Examples

Mind maps have a variety of uses in qualitative research from planning a project, collecting data, analyzing narrative and visual data, and presenting analysis strategies and findings. Figure 2 presents some uses.

4.1 Planning Research

Maps can be used to plan research. By outlining the various steps in a research project, researchers can more easily see the various tasks before them, and activities required. This might include literature review, participant identification, data collection design, obtaining institutional review board approval, conducting data collection activities, analyzing collected data, and writing up and/or presenting the data. Maps can help researchers brainstorm and plan research. They can be used before, in the place of, or even after an interview to provide additional data. Comparing interviews with mind maps from the same participant may offer a useful means to validate the data collected. Maps can also be used to demonstrate an analysis strategy

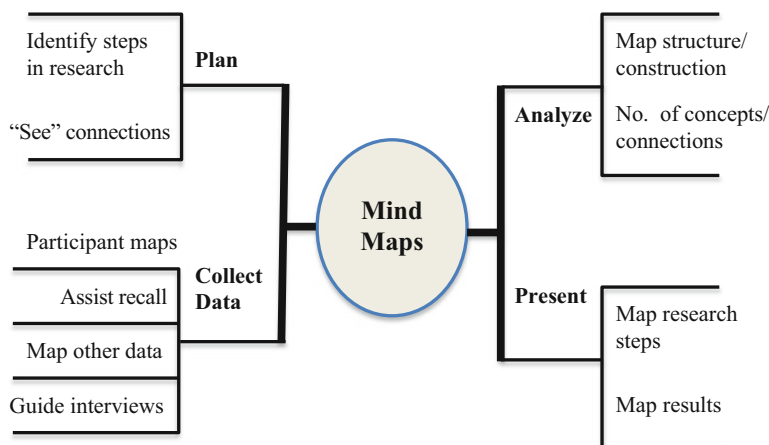
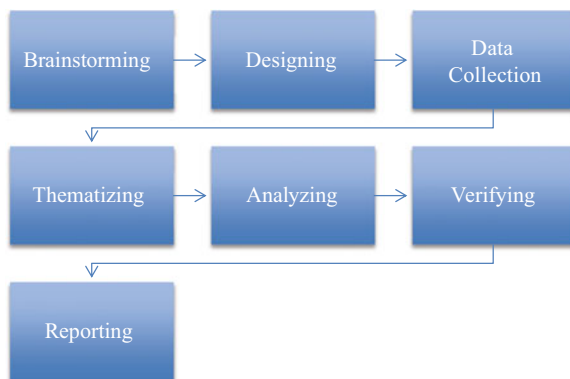


Fig. 2 Uses of mind maps in qualitative research (Wheeldon and Ahlberg 2012, p. 88)

Fig. 3 Mapping stages of qualitative research



or to present findings of interviews in a visually appealing and accessible way. Figure 3 provides one way to conceive of the stages in qualitative research.

4.2 Collecting Data

Perhaps the most obvious use of mind maps may be as a means to collect personalized and individualistic data from research participants (Tattersall et al. 2007; Wheeldon and Faubert 2009). To make one, take a blank piece of paper and turn it on its side so that it is wider than it is high. Starting in the middle of the page, make a central image or write an important word. Draw a line out from the central image in each direction and write an important theme that is connected to your central image or word. Write other words or images that are connected to this theme and continue to build your map outward (Buzan and Buzan 2000). Buzan suggests focusing one and only one word for each association and to use color, the thickness of lines, boxes, or pictures and graphics to make your map unique and expressive (Buzan 1991). Figure 4 provides an example.

There are perhaps two key aspects to mind maps that make them valuable for data collection in qualitative research. The first is that they focus on a central theme or idea and “radiate” associated ideas outward, based on related ideas and examples. The second is that they be as much as possible free form, creative, and developed by participants with minimal instruction by the researcher. This can allow the participant’s individual creative process to emerge.

4.3 Analyzing Data

Another way mind maps could be useful in qualitative research analysis of collected data. Instead of simply reading transcriptions, researchers might read, map, read, and add to their original map or decide to create another. This can allow for more flexibility to draw out different sorts of connections, relationships, or themes (Tattersall et al. 2007). It may also assist the researcher to break out of their own



Fig. 4 Example of data in a mind map (Wheeldon and Ahlberg 2012, p. 103)

cycle of assumption or expectation by forcing them to graphically represent what they are reading.

This approach to data analysis is in line with more traditional strategies derived from Pope et al. (2000). The suggestion that researchers immerse themselves in the data, identify key themes, connect these themes to concepts in the data set, and then rearrange the data based on the themes is often much easier to do graphically than textually. One approach used mind maps to show the research process from the researcher's point of view (Wheeldon 2012). This may also have the added benefit of serving as a reflexive demonstration of how themes emerged from the data (Kelle 2005). This process is represented in Fig. 5.

4.4 Presenting Data

Mind maps can also be used to present research data. They might be part of broader efforts to streamline research for policy-makers which would be an improvement over the provision of long complex data tables and the problematic assumption that readers can make sense of the complex analysis provided.

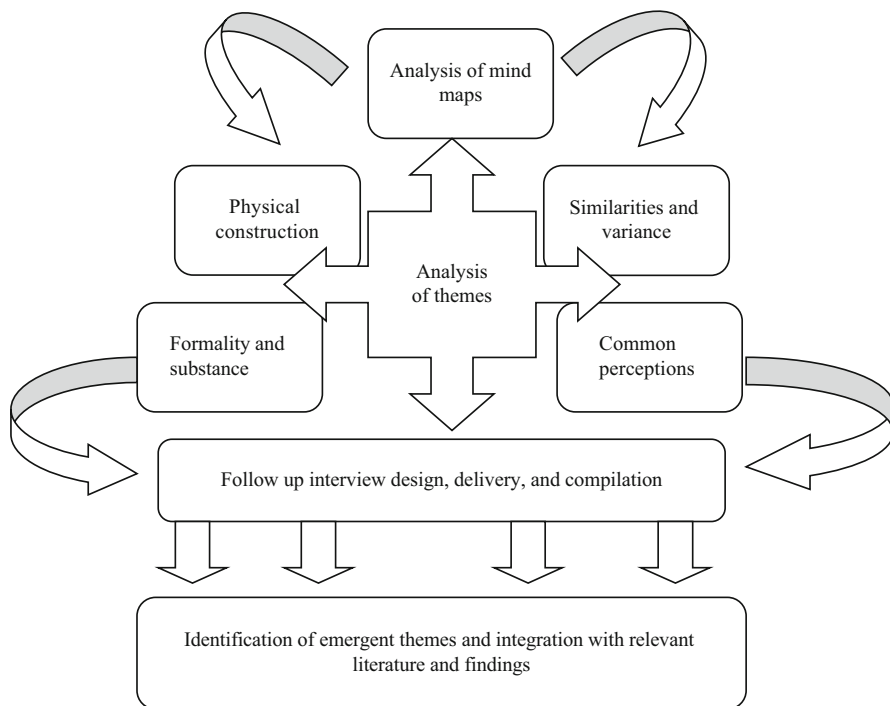


Fig. 5: Analyzing maps and interviews (Wheeldon 2012)

Beyond visual representations of research findings, maps can also be used to help students and researchers understand the nature of the questions at the heart of qualitative research. Figure 6 explores some key questions that are relevant for researchers.

5 Assessing Mind Maps: Value(s), Limitations, and Challenges

Part of the assessment of the value of mapping in qualitative research must involve to what extent they can be used to address outstanding conceptual issues. Of specific interest here is the value of maps offer a middle ground between the alternative analysis strategies offered by Glaser (1992) and Strauss (1987). Since grounded theory emerged (Glaser and Strauss 1967) as a theoretical frame in qualitative research, it has played an important role in specifying how a qualitative approach to data analysis can privilege localized understanding in theory creation. Silverman (2005) has suggested that grounded theory in general involves an initial attempt to develop categories from the data, locating the data within these categories to demonstrate relevance and developing these categories into a more useful framework for general understanding.

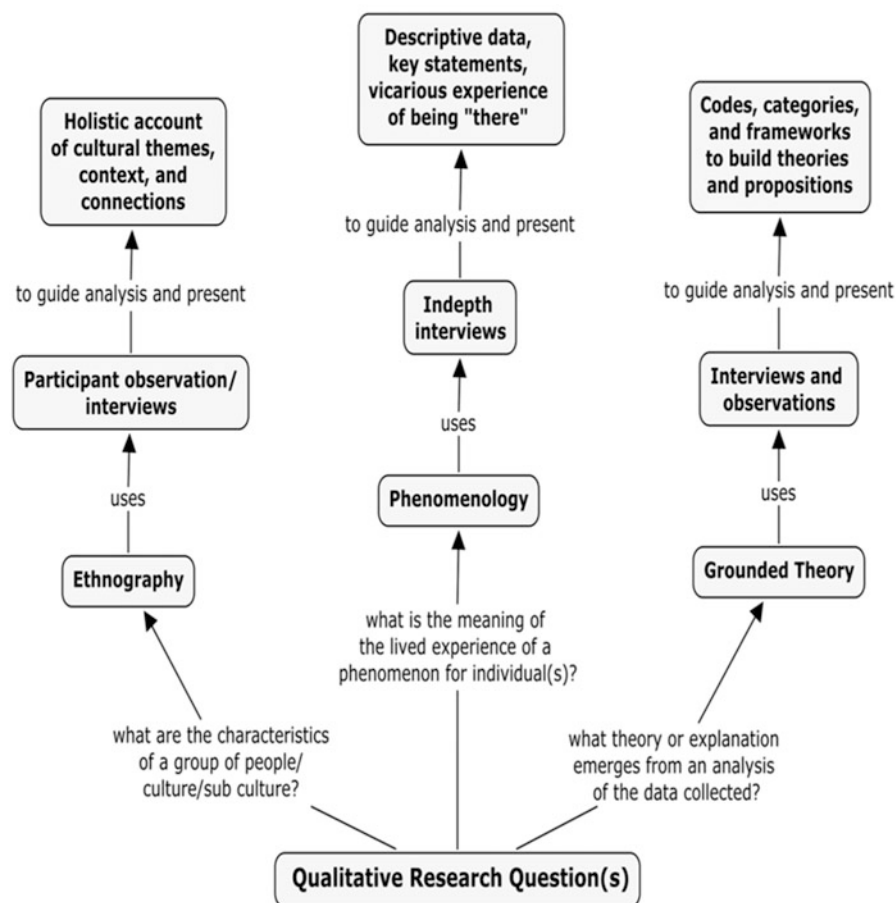


Fig. 6 Key qualitative questions (Wheeldon and Ahlberg 2012, p. 99)

However, the general agreement between Glaser and Strauss about how to analyze data from the ground up has been challenged by specific differences about how the analysis should unfold and the role and relevance of structured versus more ad hoc coding. On one view, the controversy between Glaser and Strauss boils down to the question of whether the researcher uses a well-defined coding paradigm and always looks systematically for “causal conditions,” “phenomena/context, intervening conditions, action strategies,” and “consequences” in the data, or whether theoretical codes are employed ad hoc as they emerge in the same way as substantive codes emerge, but drawing on a huge fund of “coding” families (Kelle 2005, p. 20).

Using maps in multistage data collection allows for middle ground in grounded theory. Instead of looking to the researcher to search for codes, concepts, and categories within the data, maps allow for the identification of concepts and connections based on how the participant frames their experience. As a result,

subsequent data strategies remain based on codes and concepts as demonstrated through the participant-generated maps. Although this approach might initially appear closer to the structured Glaserian strategy, subsequent data collection strategies can allow for the participant-generated framework to be tested, explored, and further detailed and delineated through interviews, surveys, or focus groups.

Of interest is that the maps provided an explicit basis for additional data collection strategies, but the subsequent themes that emerged challenged the initial analysis of the maps. In these cases, the use of maps can provide a flexible and unsolicited participant-led approach to assist coding and analysis. Because any emergent codes can be tested through subsequent data collection, the use of participant maps might be seen as a unique and innovative data-gathering instrument of interest to a new generation of more visually oriented researchers.

As described in this chapter, a variety of options exist for researchers who seek to use mind maps in the planning, analysis, and presentation in qualitative research. For those seeking to use participant-completed maps as part of data collection in qualitative research, the limitations associated with their use should not be discounted. There is evidence that important differences between people, groups, personalities, and learning styles can limit the utility of concept maps in gathering data (Rohm 1994). For example, Czuchry and Dansereau (1996) found that women identified the mapping assignment to be easier than did men. However, in my own work, some participants did suggest that they found the initial request for a map “odd,” and the process of creating a map “strange.”

Another limitation is based on the definitional confusion that exists in studies and discussions of concept maps and mind maps. Often, it appears, these two distinct types of maps are combined and referred to as though they are the same (Nesbit and Adescope 2006). This is a problem given the theoretical basis for mind maps, and the need to balance the practicalities of collecting and assessing data, with the need in qualitative research to ensure the prioritization of the participant’s experience. In some studies, the use of maps as part of qualitative data collection resulted in the return of maps that did not conform to traditional definitions (Wheeldon and Faubert 2009). This may be a training issue, but it also may be related to how people view experience. As Tomas (1997, p. 75) has suggested, “recall of experience is always selective and there will be many absences or gaps. People forget things or choose not to tell things or are not aware of things – for all sorts of reasons.”

This highlights a central issue for visual approaches in data collection. On the one hand, understanding how data based on a common definition is important. On the other, definitional requirements may be at odds with a focus on precision, credibility, and transferability as they relate to capturing individual experiences and perceptions in qualitative research (Tattersall et al. 2007).

This definitional concern is also shared by those who draw a sharp distinction between data visualization based on rigorous statistical models and infographics, which may be exciting and/or visual appealing but not logically organized or consistently designed (Gelman 2011). The question is not which is better, but which is best suited to what sort of goal. This distinction is important for concerns related to visual data collection. Different assumptions must inform

the consideration about which types of maps are best suited to address specific research designs and research questions (Wheeldon and Ahlberg 2012).

6 Mind Maps and Mixed Methods

Few doubt the value of mixed methods approaches to combine the clarity of counts with the nuance of narrative reflection (Wheeldon and Ahlberg 2012). New perspectives have also emerged that consider the challenges posed by partnerships between qualitative and quantitative approaches through the construction of mixed methodologies (Johnson and Onwuegbuzie 2004; Poole and Davis 2006; see also ► Chap. 4, “The Nature of Mixed Methods Research”). Using maps as part of mixed methods research can help fuse qualitative assumptions about value with quantitative approaches to capturing frequency. For example, using mind maps to collect data ensures the reflections that emerge are coming from the participant themselves rather than being prompted through series of survey or interview questions.

This could involve using mind maps as a pre-/posttool to compare number of concepts and/or complexity of the map’s construction. It might involve the use of mind maps as a qualitative data collection tool that could be used to identify a list of key concepts for inclusion in a survey that would lend itself to numeric analysis. One approach involves the use of mind maps to create a mixed methods measure (Wheeldon 2010). Imagine 4 phases of data collection. First data are collected through open-ended mind maps from participants. These data are then sorted and organized to identify key themes that might be explored through more general open-ended and then more specific close-ended interview questions. As part of a final conclusionary or summative data collection phase, participants could be invited to revisit key ideas that they would want to make sure were captured as part of the research. These different phases are more or less participant centric. This allows a weighting process to privilege user-generated concepts consistent with qualitative researcher’s focus on the “experiences, perspectives and histories” (Ritchie and Lewis 2003, p. 3) of participants.

For example, concepts that emerged through mind maps could be scored at 4 points. Concepts that emerged through open-ended questions could be worth 3 points, and those that emerged through more close-ended or specific questions worth 1. Concepts that re-emerged during the summative stage of data collection could be worth 2 points. A concept that emerged through all four phases would be scored at 10, while those that emerged from a close-ended question only would be scored at 1. In general, the more user generated and unprompted, the higher the score of salience.

7 Case Study: Mind Maps: Priming the Pump, Depth, and Detail

The Latvian Legal Reform Project (LLRP) was a 20-month initiative funded by the Canadian International Development Agency (CIDA). It ran from 2002 to 2004 and offered targeted legislative support, institutional capacity development, and human

resources training to the Latvian Ministry of Justice as it established the National Probation Service (NPS). Ministry officials developed new laws, amended existing laws, trained staff, assisted in policy development, and provided support to leading officials from other related Latvian ministries. The Latvian Probation Service established in 2003 has since grown year by year in number of staff, programs, and services delivered (Jurevičius 2008).

In one study, a mind map methodology was used as part of a 4-stage data collection approach (Wheeldon 2009). Originally, participants were asked to complete mind maps between September and December 2007. This proved impractical. At the advice of senior colleagues, instead of gathering data for all participants using mind maps, researchers split participants into two groups. One group completed a mind map before data collections through a series of interviews, and one group did not. While not initially envisaged, this iterative approach allowed another sort of map-based analysis. The first contained 14 participants who completed both stages of the data collection. The second contained five other participants who completed only the interviews.

In past projects, the maps themselves served as a valuable source of data (Wheeldon and Faubert 2009). This study focused on the responses of participants through notes I took during the interviews. Of specific interest in this analysis was whether the completion of a map would impact the depth and detail of individual reflections. In this study, depth and detail were defined using the following criteria. Detail was related to the number of unique concepts provided within all interviews, including the reflective or summative responses. By contrast, depth was connected to the nature of the interview responses based on the length of responses, complexity of connections made, and specificity of the examples provided.

The results of the interviews among both groups were compared, based on the number of individual concepts identified through the interviews, and the length, detail, and number of specific examples provided through the participants' responses. By combining an analysis of the presence and frequency of unique individual concepts, along with the specificity of participant reflections, broader comparisons between these groups became possible. In this study, mind maps appeared to "prime the pump" of participant reflection. By requiring research participants to first frame their experience, maps may help researchers in the refinement of other data collection strategies. In this study, the group who had completed the maps before the interviews identified, on average, seven more individual concepts than the group who did not first complete a map, as presented in Table 1 (Wheeldon 2011).

Table 1 Average number of concepts identified by map and nonmap groups

Map status	Average number of concepts
Map	16.57
Nonmap	9

In addition, participants who completed maps provided more depth when recounting their experience during the interviews. This included a greater number of specific examples, memories, and suggestions (Wheeldon 2011). When asked to reflect on the experience of creating a concept map, virtually all participants in the map group identified the maps as a “useful way to see experience.” Some suggested this was because making a map “helped them to remember events from years ago” and “organize their thoughts about the experience systematically.” Others suggested that, as a visual aid, it helped put the experience in “context” and provided a “clearer view” by looking at events again, realizing how much had happened, and helped them to “focus on the key experiences, concepts and connections.”

The notion that qualitative researchers ought to consider the value of numeric-based means of analysis in their research is controversial. As Sandelowski (2001) points out, a perception exists that real qualitative researchers do not count. While simplistic, given the utility of numbers to present what is known about a problem, and describe research samples, this aversion to numbers speaks to broader political and ideological differences between qualitative and quantitative research agendas (Jick 1979). While the hallmark of past academic debates, it seems quaint and somewhat outdated given the complexity of emergent research problems social science researchers face today. Instead of propagating antinumeric myths, qualitative researchers would do well to use numbers to showcase the labor and complexity of qualitative work and examine in more detail the meanings that may emerge from qualitative data. While the over-reliance on numbers and counts may be problematic, an under reliance may be just as dangerous.

8 Mind Maps and Health and Social Sciences

Visual maps have become a central methodological tool in the fields of nursing and health studies. Studies have employed maps as part of nursing education (Rooda 1994), care planning (Mueller et al. 2001; Kern et al. 2006) and for reflection and evaluation (Jenkins 2005). This trend can be connected to what is known as a genogram. Defined as a pictorial display of a person’s family relationships and medical history, it may include visualized hereditary patterns and psychological factors that inform relationships (McGoldrick et al. 1999). Today, mind maps are essential tools in qualitative research in these fields (Tattersall et al. 2007). They can be differentiated by those who view maps as a tool to assist in teaching and learning in nursing and medicine, those who have used maps to understand professional values and views, and those who have outlined the application of mapping techniques as part of qualitative methodologies and approaches.

For teaching and learning in medicine, using maps improved recall the massive amounts of content and complex inter relationships between them (Farrand et al. 2002). Maps have been shown to be one example of a creative strategy to make learning both more interesting and more fun as part of nursing education (Rooda 1994). Mind mapping assists students to engage in a unique method of learning that can expand memory recall and help create a new environment for processing

information (Kotcherlakota 2013). For example, research by Farrand et al. (2002) explored mapping as a memory aid among medical students. Students who used mind maps saw a 10% increase in recall over baseline versus students who used their preferred study methods who only had a 6% increase over baseline.

Others have explored how maps can assist students to understand nurses' attitudes, values, and behaviors. For example, Stephens (2015) found that nursing students felt that by sharing initial mind maps in a content area and receiving feedback from peers and faculty, they were able to better understand both key concepts and attitudes and values congruent with the profession. This might be connected to how mind maps have been shown how to establish trust between those collecting health data and participants and/or patients. Mind maps can serve as a means to obtain participant verification of an emerging theoretical framework and establishing trust between the research and participant (Whiting and Sines 2012).

Perhaps the most detailed use of mind maps as a tool is by Tattersall et al. (2007). They identify transcribing and analysis. Mind maps can serve assist traditional transcribing, as a complementary approach used in conjunction with traditional data gathering techniques in health sciences. For example, to augment data collected through written transcription or interviews, the researcher can use mind maps to document or capture nonverbal communication such as eye contact, posture, facial expression, personal space, and touch. While mind mapping and transcribing verbal interactions would be difficult, a mind-mapping research assistant could observe the interaction, and add important, relevant data (Tattersall et al. 2007).

The use of maps in analysis could involve using visual techniques to bracket preconceived ideas and thus, limits the potential they will interfere with subsequent analysis. If conducted correctly, mind mapping should lend itself well to this style of thought process, as it allows freethinking or, as Buzan and Buzan (2000) state when discussing the aims of creative mind mapping, "to clear the mind of previous assumptions about the subject" (Tattersall et al. 2007, p. 33). Beyond bracketing, maps can be used to identify themes including issues, concepts, and ideas derived from the raw data. Mind maps can also be used to index these themes by linking them throughout all respondents' data. Tattersall et al. (2007, p. 33) also identify charting, whereby the data are rearranged into "charts" containing the relevant data from various respondents.

9 Conclusion and Future Directions

Traditionally, qualitative data collection has focused on observation, interviews, and document or artifact review. Building on past work on visual approaches in the social sciences, in this chapter I considered the value(s) of mind maps for qualitative research. Qualitative researchers can benefit from visually oriented approaches to research, especially when they offer a graphic and participant-centric means to ground data within theory, focus on how user-generated maps can assist participants to better frame their experience, and justify the design and development of additional

data collection strategies. This is based in part on an imperative to develop models of knowledge that capture data that are freely “given” by participants (Drucker 2009).

The visual turn in social science research is likely to continue and embrace more technological tools and techniques. At the same time, many may continue to use mind maps as a process of artistic and imaginative reflection to capture one’s experience. While future applications of mind maps are likely to use technological tools and techniques, there is value in the original approach of putting pen to paper and engaging in a creative and tactile process of outlining ideas and recounting experiences (Buzan 1974).

Mind maps can be connected to broader trends away from the traditional positivistic practices of researcher-led data collection and toward more subjective explorations of phenomena including how creative explorations spark new ways to interrogate meaning (Lippens and Hardie-Bick 2013). Given the myriad of research decisions (Palys 2003) that are made in the construction and analysis of any study, the acknowledgment of the potential for researcher bias is an important contribution to social science research. New visual approaches to data collection might offer another means to explore reflexive analysis within qualitative research.

It is worth repeating that perhaps one of the most interesting features of mapping is that it can allow participants to break out of the rehearsed narratives of their daily lives (Hathaway and Atkinson 2003) and provide an entry point into the unadulterated views of participants. Through the graphic construction of experience, researchers can get another view of how participants see the world (Wheeldon and Faubert 2009). Such approaches are of interest in many fields and disciplines in the social sciences. As I have demonstrated in this chapter, they have particular relevant to the health sciences.

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Creative Insight Method Through Arts-Based Research

64

Jane Marie Edwards

Contents

1	Introduction: What is Arts-Based Research?	1132
2	ABR Methodology in Healthcare	1133
3	The Theoretical Location of ABR	1134
4	The Arts and Health	1136
5	Arts-Based Research in the Creative Arts Therapies	1136
6	Arts-Based Research: A Narrative Example	1138
7	ABR: Where Does the New Researcher Begin?	1139
8	The Foundations of Creative Insight Method	1140
8.1	Narrative	1141
8.2	Poetry	1142
8.3	Visual	1142
9	Conclusion and Future Directions	1142
	References	1143

Abstract

Arts-Based Research (ABR) has gradually developed momentum across many disciplines. It represents a way of using the arts to facilitate and enhance processes within research and even to conduct entire research studies. It can be used within healthcare research and in research studies with participants who are vulnerable. ABR approaches use any type of arts creation processes including poetry, narrative fiction, painting, drawing, or song writing. This chapter presents three levels of ABR researcher – novice, emergent, and expert. Examples from these three levels are presented and proposals for tasks and exercises to begin ABR as a novice to this method are described. A critical awareness of the ways in which ABR exists as a stand-alone method, and also aligns with other

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contemporary developments in qualitative healthcare research, is presented and discussed. The choice of studies reported here reflects the author's expertise in creative arts therapy. Providing this context and background helps new health researchers using ABR to position and expand their approach to the methods of their inquiry. Processes in choosing a method are described, with reference to multiple opportunities afforded by ABR. The chapter additionally elaborates a contemporary approach within ABR developed by the author: Creative Insight Method. This method will be presented in terms of ways of facilitating safe and collaborative arts-based processes with groups.

Keywords

Arts-based research · Music therapy · Arts therapy · Expressive therapy · Constructivist epistemology

1 Introduction: What is Arts-Based Research?

Arts-Based Research (ABR) represents a way of using the arts to facilitate and enhance processes within research, to advance knowledge (Malchiodi 2017). ABR has gradually developed momentum and impact across many disciplines. ABR approaches can involve creating works such as poetry, narrative fiction, plays, painting, drawing, or song writing. In her ground-breaking text, Leavy (2015) identifies six types of Arts-Based Research: narrative inquiry, poetry, music, performance, dance, and visual arts.

Boydell et al. (2012, np) describe ABR as being both “(1) a process to produce knowledge, and (2) a product to disseminate results.” In the broadest conception of ABR, the method can be used as the primary approach to research within a project or can be used within a specific part of a research study. ABR has been used in healthcare research (for example, McCaffrey and Edwards 2016) and in research studies beyond healthcare with participants who are vulnerable (Osei-Kofi 2013). The researcher can be responsible for generating the arts-based components, perhaps in response to narrative data, or the participants can create the art materials. The researcher can also use the arts to reflect on and amplify data, deepening insights and reflections.

Jones (2015) has recommended that engaging the arts, and artistic processes, is a much needed *fresh inspiration* in the ongoing development of qualitative methods research. Chilton and Leavy (2014, p. 403) have proposed the appeal of ABR results from the capacity of the arts to

...promote autonomy, raise awareness, activate the senses, express the complex feeling-based aspects of social life, illuminate the complexity and sometimes paradox of lived experience, jar us into seeing and thinking differently, and transform consciousness through evoking empathy and resonance.

At its core, ABR rejects any distinction between the sciences and art. It is proposed, instead, that all forms of inquiry and processes of knowing require, and result from,

curiosity and creativity (Jones and Leavy 2014). Equally, ABR, perhaps due to its emergent character, currently remains free of disciplinary prejudice or any kind of theoretical expectations (McCaffrey and Edwards 2015).

In this chapter, three levels of ABR are presented with the encouragement that the researcher chooses the ABR approach most suitable to their journey as a researcher. Level one is conceptualized as referring to the novice ABR researcher. In level two, the emerging ABR researcher is represented. Level three refers to the experienced and/or expert ABR researcher. Distinguishing these levels is intended to provide support to researchers looking for a way *in* to ABR methods, and for those who are reviewing ABR proposals, or scholarly papers, who may not have encountered the approach before. The idea of boxing up ABR into levels of practice is somewhat at odds with the freedom of ABR methods. Therefore, the caveat that this is just meant as a useful device for people new to this field of research, and something I have found helpful in ABR method with university students (Table 1).

At Level 1, the processes in ABR are presented as arts and action based and may exist somewhat apart from theory. However, even while the researcher at the earliest stage may not be engaging theory development, it is important to have a senior adviser/mentor or research supervisor. This person must have theoretical competence to help fan the tiny sparks of creativity that may, at a later stage of the research journey, blaze into highly promising theoretical contributions. At Level 2, identified as *emergent*, the arts become more central to the ABR method chosen, and at Level 3, an *expert* level, the qualities of a fully integrated ABR project are available to the researcher.

2 ABR Methodology in Healthcare

Qualitative methods in healthcare developed as a reaction to the dominance of empirical methods. Many authors claimed that insights gained from service user engagement with treatments, and services, were marginalized and silenced (for example, Dyck and Kearns 1995). Finding ways to represent these hidden aspects of treatments, patient experiences, and services was needed (Pope and Mays 1995).

Some authors using ABR methods have noted the hesitancy of acceptance of these methods (Jones 2015). Reflecting on their experience of developing ABR projects, Einstein and Forinash (2013, p. 84) identified that they were aware of their fear, “that art is not enough and will not be understood.” Within the rationality of healthcare decision-

Table 1 Descriptions of ABR levels

Level 1 – novice	Level 2 – emergent	Level 3 – expert
Arts informed	Arts based	Performative
The arts are used as a way to reflect on research data – to contribute to deeper understanding of the phenomenon under investigation	The arts form part or all of the data used to discover and develop the topic under investigation	The arts are both the process of the inquiry and the outcome. The result is a live or recorded performance

making, there is suspicion of the emotion or sentimentality that might be associated, or even evoked, through the research outcomes which involve the arts (Jones 2015).

In spite of the observations that ABR has been met with skepticism, and is not easily accepted in healthcare, multiple ABR studies based in healthcare sites or dealing with healthcare issues have been conducted. A scoping review by Boydell et al. (2012) found 71 healthcare studies that met their documented criteria for ABR. The most common rationale they found for employing arts-based process in research was with the goal to highlight and explore the illness experience of patients. A secondary intention they identified was to challenge existing practice in healthcare, with the goal of improving services to patients. A report of a play about the experiences of men with prostate cancer and their partners (Gray et al. 2003) is an example of achieving these goals through conducting ABR in a healthcare context. The play was performed for health professionals, who were then interviewed about their responses to the play. Participants reported that they experienced a new awareness or understanding about the issues facing men with prostate cancer; the play reinforced health workers' positive attitudes and behaviors in relation to patients; attending the play resulted in participants having an increased sense of connection with ill people; for some health worker participants, the play prompted them to alter their clinical practices to more effectively meet their patients' needs.

A similar review of ABR studies in healthcare found 30 studies (Fraser and Sayal 2011). Drawing out patients' experiences of illness and treatment were found to be the primary reasons for undertaking ABR studies. The authors noted that many of the studies they reviewed involved seriously ill patients with life-threatening conditions. They indicated that the arts were engaged because for such patients "their experience, associated feelings, and perceptions are not easily described in words" (Fraser and Sayal 2011, p. 138). They observed the growth in popularity of these methods, but they also documented their concern regarding the absence of critical debate about the applicability of these methods.

3 The Theoretical Location of ABR

The novice ABR researcher may wish to skip over the short theoretical section presented here. This is understandable. You are new, enthusiastic, and you want to *get on with it*. You cannot understand why so much is written in this section and most of it in a scholarly language that takes time and effort to understand. Feel free to skim this section and move on. At some stage during your research reporting process, you may be challenged by a reviewer, or the question of a conference attendee, or even an examiner for a thesis, and you then might find this tiny section on theory helpful in further developing your understanding and preparing your response.

The process of research inquiry should draw you into deeper reflection, and it is common that this process may well bring confusion, and even uncertainty, before clarity emerges (Edwards 2012). Courageous exploration into the theoretical unknown is encouraged, whether you are an undergraduate student skimming this while trying to finish an essay or an experienced researcher seeking fresh territory to explore.

Bourriaud's *relational aesthetics* (Bourriaud 2002) is increasingly relevant to the philosophical parameters of all practical endeavors in ABR. In relational aesthetics, all participants in the arts are active in the creation of a work. These active participants include the viewer or audience and the primary creator. Bourriaud described this process of engagement in art between multiple parties including viewer and creator as a *transitive ethic*, that is, in order to complete its meaning, the work of art must be viewed or experienced beyond the sole perception of the artist. For Jones (2015, p. 87), this relationality has the quality of,

...inter-subjectivity, being-together, the encounter and the collective elaboration of meaning, based in models of sociability, meetings, events, collaborations, games, festivals and places of conviviality.

As research methods are increasingly constrained by needing to align with either qualitative (social science), quantitative (empirical, experimental), or what is termed *mixed methods*, it is refreshing to find that ABR is unable to be easily categorized within any of these. ABR accesses the potential fun and playful messiness of the arts and offers what Viega (2016, p. 3) has described as “boundless possibilities for inventiveness, discovery, and creativity.” A constructivist sensibility can provide the researcher with new experiences leading to greater insights into the creative potential of our humanity.

Many expert ABR projects do not easily fit within a single *genre* or type, instead combining, or interweaving, multiple perspectives from a range of forms. For example, in McClaren's study (McLaren 2000) of menopause as experienced by 12 artists, she used multiple data forms including visual diaries, interviews, and art works. Her interpretation and processing of the materials was examined using a range of lenses including “feminist post-structuralism, phenomenology, narrative inquiry, art, and medicine” (Hopkins 2008 p. 259).

In their introduction to an inspiring book on ABR, Liamputtong and Rumbold (2008) describe how, at the time of writing, reports of ABR projects focused on *propositional* knowing rather than the more congruent experiential or *presentational* knowing that first-hand engagement with the arts involves. In the time since they wrote, *experiential knowing* could be described as a new force in analysis of data and representation of results. The signs for this emergence are clearly outlined in the text they developed and edited.

Woods (2011a), a medical humanities researcher, has suggested that the limitations of narrative need to be acknowledged when presenting the experiences of healthcare service users. Woods' concern lies with the assumption that all humans have a narrative self and can express their experiences in narrative. She proposed that her field is in *thrall* to narrativity (Woods 2011b). In relation to the arts, many art forms are predominantly nonnarrative such as visual arts, music, and dance. However, written or spoken narrative can become a strong force in explaining or presenting such works within ABR. There is more terrain to be explored in relation to the complexity of assumptions within ABR and their relevance for greater criticality within ABR that can include, but also exclude, research practices based on an extant philosophy of experience.

Many ABR projects at the expert level combine, or interweave, multiple perspectives from a range of forms, creating new forms which need new theoretical language in description of the processes engaged. For example, Allegranti (2013, p. 397), in presenting *Becoming Bodies*, describes how her research process “demonstrated a material-discursive engagement where I encompassed a recursive loop between felt-sense movement improvisation and language.”

ABR is, and should continue to be, theoretically diverse, engaging complexity and contributing to theory building in healthcare practice.

4 The Arts and Health

ABR has developed alongside the arts and health movement. The arts have a long history within the provision of healthcare in many countries. However, with the rise of the dominance of rationality in evidence-based healthcare services, the arts were increasingly relegated to entertainment and diversion rather than included as a way to offer psychological support to people coping with illness, hospitalization, and even pending death. In recent times, the arts have had greater impact and engagement within healthcare, notably through some art councils having programs devoted to arts and health with accompanying policy documents. For example, in Ireland, <http://www.artscouncil.ie/Arts-in-Ireland/Arts-participation/Arts-and-health/>. Some practitioners have considered the need for the arts to address *aesthetic deprivation* in healthcare, proposing that “arts and health programmes. . . provide the nexus for reflection and action in implementing a range of aesthetic enrichment in health-care setting” (Moss and O'Neill 2014, p. 1033).

In Western healthcare, multiple examples can be found where the arts have been promoted by dynamic and passionate individuals. For example, Cunningham Dax, a psychiatrist working first in London, and then in Australia, through the second half of the twentieth century, collected patient's art works on paper with a view to using the imagery to better understand the lifeworld of the patient (Harris 2014). Originally called *psychiatric art*, the images provided insights into diagnoses, experiences of living with debilitating conditions, and were categorized according to conditions, but also experiences. The work on display in the Cunningham Collection in Melbourne is only permitted to appear with the approval of the art maker.

Recently, the emerging field of arts and health has appeared in medical journals (for example, Moss and O'Neill 2014). Arts and Health has emerged as a field of its own with journals, conferences, and disciplinary groups existing in, and across, many countries.

5 Arts-Based Research in the Creative Arts Therapies

Creative arts therapist have demonstrated reluctance to describe their research method as ABR. I have previously explored this reluctance by undertaking a review of ABR in the creative arts therapies with a colleague (Ledger and Edwards 2011).

Our findings reported multiple examples of arts-based processes in music therapy research projects that had not mentioned, nor aligned with ABR. In considering why this occurred, we suggested that it is:

...possible that music therapy researchers are reluctant to explicitly adopt arts-based research practices. This could be due in part to a desire to ensure that music therapy research is accepted as scientific and scholarly within the dominant traditions of healthcare research (Ledger and Edwards 2011, p. 314).

In further commentary, I have suggested that music therapy can be observed as a profession which has demonstrable social status anxiety (Edwards 2015). This was in response to concerns raised in a paper about the way that disability studies could benefit considerations of music therapy practice (Cameron 2014). This status anxiety may have contributed to the absence of the creative option of ABR within research studies and the reluctance to name it as such when it appeared.

However, times change. Recently, I accepted an invitation to serve as guest editor for the *Journal of Music Therapy*, the first music therapy journal to focus an entire issue on ABR. I was able to call upon my colleagues and showcase the uniqueness of ABR; integrating and honoring the multiple ways human knowing and perceiving can be explored, represented, and enacted.

One of the papers in this special issue, Carolyn Kenny's *performative writing* piece (Kenny 2015) reflected her extensive research and practice experience as an Indigenous scholar and a creative arts therapist. She engaged imagined dialogues with the many scholars she has collaborated with, and undoubtedly influenced, while acknowledging her muses and intellectual roots. Performative writing can be provocative, and even *difficult*, while also having the quality of bringing the reader into close contact with the experience of another (Rath 2015). Readers who are not familiar with reading philosophical texts, or who have not encountered postmodern concepts in their research to date, might find the genre of performative writing challenging to engage. However, bringing curiosity and an open mind to reading, such works will bring rich dividends. Be prepared to understand that this way of writing is not always immediately self-explanatory; it wends and weaves through many complex concepts. The reader is encouraged to engage states of contemplation and stillness to gain the best insight from such work.

Also in the same special issue of JMT, Gilbertson's (2015) creative engagement with ABR was demonstrated through his research study of music therapy practitioner experiences. During an interview in which they were asked about an experience from their practice, clinicians' hands were submerged into silicon solution and cast in the position that they recalled from that prior moment. The reader is drawn deeply into consideration of the impacts of the findings.

Ledger (2010, 2016) used poetry writing to develop a response to narrative materials generated by participants' descriptions of their experiences founding new programs in healthcare. She described her process of developing the poems as follows:

I re-read a narrative, identifying words or phrases that seemed particularly significant or meaningful to me. I then wrote one or two poems in response to the words or phrases that I had previously identified. By the end of this procedure, I had written twelve poems in all (Ledger 2010, p. 121).

As Ledger's doctoral supervisor, I remember her first poem sent to me and the responsibility to encourage her efforts with delight. She often said that my excitement and enthusiasm for the poems as she created them inspired her to keep going with the work. The delicate work of encouraging creative flow while supporting scholarly depth and exploration is a key to collaboration and support for ABR projects.

McCaffrey (2014) demonstrated how song writing acted as a means to process her uncertainty about a self-portrait image drawn by a participant in an arts-based focus group about mental health services participation (McCaffrey and Edwards 2015). Similarly to Ledger (2010), she used her own reflections on the materials to generate an arts-based response.

Within ABR, there is acknowledgement of the important place for research methods that can facilitate and honor thinking, feeling, and reflecting for all research participants, including the person developing the research and the people who participate or co-research with them. This orientation within the ABR epistemology offers a way to bring multiple perspectives into research processes and to deepen reflection on data and findings. In the midst of the *playful messiness* (Edwards 2015) that ABR inspires, novel insights, and new dynamics of scholarship, can be engaged.

6 Arts-Based Research: A Narrative Example

Inspired by Bochner's considerations of narrativity (Bochner 2012), I have recently prepared research reports using narrative inquiry (for example, Edwards 2016; Edwards et al. 2016). I have also coauthored a chapter about this research approach (Hadley and Edwards 2016). Ideally, ABR should be determined as belonging to the research processes from the planning stage. However, similarly to Ledger's experiences (Ledger 2010), I recently found in analyzing interviews with child play therapists about their understanding of the United Nations Convention on the Rights of the Child (Edwards et al. 2016), that narrative materials might evoke a response that was not anticipated at the planning stage of the study. I prepared four stories or *vignettes* based on the stories told by the therapists during the interviews. I carefully checked the ethics of this procedure. To assure confidentiality of the children in the stories, I changed certain details and checked back with the interviewees that they agreed the stories they told about children's experiences were adequately disguised in order to be publicly available.

Below is one of these vignettes, *Baby sister*. In the story, I reanimated various aspects of interview data from play therapists voicing the story from the child's perspective.

Baby sister:

When my new baby sister was born, I had great fun playing with her. When she looked at me, she always smiled or laughed. I could put my head down on hers and then breathe and make gurgly noises and she would giggle. One day, I saw Mum crying and then heard sirens and a policeman came and sat on the couch. I don't know what happened but Mum was always sad after that. The policeman told me my sister was dead. I asked him when she would be coming home again and even though he was a policeman, he couldn't answer the question. I had to go and live with my Dad because Mum was too sad. Dad took me to a place where I met Sally who had a big room full of toys I could play with in any way I liked. Sometimes, I bashed and crashed things in there which made both of us laugh a lot. Sometimes, I wanted to set up the toys so one doll was my sister who died and then one doll was Dad, until I had the dolls and teddies all lined up with their names. My Mum came to see me at Dad's and she always brought me a present. One day, I asked Mum why she was getting really fat. She laughed and said that she was having a baby. I felt scared. What if this baby died too and would it be my fault? I asked Sally whether this baby would die too. Sally said some babies die but not all babies. That was good to know. She said I had been a baby too when I was younger and I am alive. I did not realize that. I asked Mum if there were some photos of me as a baby. She searched for a long time, and then she found one. I looked at it and thought I looked a bit like my baby sister who died but maybe babies all look the same. When my new baby sister was born, I loved playing with her. She liked it when I put my head down onto hers and breathed and made sounds. She would laugh and laugh. One day I was told I had to say goodbye to her. She was going to live with another family. I really could not believe it. It was like being dead but in a different way. I said goodbye to her and played all our usual games. When I was back in the car with Dad, I didn't know whether I was going to cry or laugh so I ended up just sitting there saying nothing. My baby sister made me laugh so much so it was sad to think I would never see her again. Sally helped me to write a story about things like how I had played with my baby sister and how much I loved her. I drew the pictures, and at the end of the story, there is a photo that Mum took of me and my baby sister. I hope one day I will see her again. I hope it is not my fault she will not be part of our family any more.

Narrative researchers have described vignettes written in this way as *factional stories* (for example, Kallio 2015). A merger of *fact* and *fiction*, the story is marked as an imaginative invention based on factual details of a real situation. The term *creative nonfiction* has also been used indicating that writing in this way can have the purpose of "... engaging readers' emotions [to] enable vicarious experiencing of reported events – to feel them, and their outcomes – with a view to enhanced understanding" (Vickers 2014, p. 961).

7 ABR: Where Does the New Researcher Begin?

Ledger and McCaffrey (2015) propose four questions which are helpful for the new researcher approaching ABR with curiosity: (1) When should the arts be introduced? (2) Which artistic medium is appropriate? (3) How should the art be understood? and (4) What is the role of the audience? Each of these questions assists commencement of an ABR study. It may be that the researcher only wishes to employ arts-based methods after the research has commenced. The introduction of the arts might align with a wish to deepen an understanding of some aspect of the data, or it may only be

realized post hoc, that the project has engaged an arts dimension. For example, if a reflexive journal is kept, it may be that this document includes narrative or poetic forms, and these might be reworked to further inform the analysis, and reflect on the findings.

8 The Foundations of Creative Insight Method

My approach to ABR, termed Creative Insight Method, was developed through work with groups of therapy trainees in my role as Head of Training in music therapy at the University of Queensland for 7 years and at the University of Limerick where I was Course Director of the Music Therapy training for 14 years. I currently teach at Deakin University where I have developed new curriculum in teaching therapy trainees about use of the self in practice. I have developed a series of exercises that can assist trainees to expand their concept and techniques of self-awareness. I focus on enhancing insight as the goal of the work within the context of self-development that is an essential part of training for therapy work (Edwards 2013). I have also had the opportunity to apply these skills with practitioner groups in Australia, Ireland, and the UK who have invited me to lead self-development sessions for staff teams.

I draw on participants' creativity by offering the opportunity to make work together or individually in the group. My intention is to promote insight and self-awareness through *experiential knowing*. Insight is described in the therapy literature as a way of perceiving what is happening in therapy that is distinct from an intellectual understanding or theoretical interpretation (Jørgensen 2004). As Jørgensen (2004, p. 529) has indicated:

Part of what the good therapist has to offer is different perspectives on the self and reality – perspectives that open up new forms of behavior and new ways of relating to others. . .

I would also add to this that the therapist's capacity to listen closely, attentively, and with reference to bodily sensations, impressions, and even fleeting thoughts allows a person who is often quite distressed to feel psychologically *held* and supported. The ability to experience and discern one's reactions, and emotional states, and use these to reflect upon the interpersonal dynamics occurring within therapy sessions is a key to competent practice within relational therapy traditions (Bateman and Fonagy 2011). As Kumari (2011, p. 213) has identified:

A heightened awareness of the self is seen as a fundamental aspect of the majority of approaches to therapy . . . Adequate self-awareness is also essential to ensure that the therapist does not become completely overwhelmed by seeing clients who are often extremely distressed.

This self-awareness needs to be *cultivated* in an ongoing process of committed practice and habits (Geller and Greenberg 2002). In the section that follows, suggested tasks for research classes, students, or practitioners new to this approach

are presented. These are all processes I have engaged in teaching ABR to groups, or in facilitating group processes through *Creative Insight Method*, the approach to ABR that I have developed. For the purposes of using this approach, it is presumed that group leaders, and academic teachers, will have at least basic knowledge of psychological safety when working with groups. That is, participating and sharing are optional, students are asked to pay attention when someone is sharing (no digital distraction permitted), and facilitators will remain connected and sensitive to what the group produces during the creation process, and when reporting. The tasks cycle through *action* then *reflection*. The participants are encouraged to share but their safety is more important than overt participation. If people are shy, or reluctant to present for some reason, this should be respected.

Usually, I start with a short presentation in which I introduce myself and talk briefly about Creative Insight Method. I work to set a contemplative mood by grounding myself, speaking calmly and creating a quiet atmosphere. After this introduction, I ask people to sit quietly and listen attentively to all the sounds they can hear inside and outside the room. I ask them to gradually bring their attention into the room and then their bodies, focusing on their breathing, slowing and deepening their breath. I spend a few minutes doing this and then ask them to bring their attention back into the room. After setting up this atmosphere of relaxation and thoughtful focus, I introduce the arts process. I have described some options below that readers may wish to try.

Challenges I have experienced include people arriving late and disrupting the flow of the group, the group not being the right level of maturity to engage the work, or individuals in the group being overwhelmed in some way by the task set for them. Sometimes, participants have cried when they start to write or paint, or for some reason they cannot tolerate the solemn feeling of quietness and need to disrupt it. When participants are not able to engage in a more contemplative way, I might switch to a more playful style with humor and lightness of focus. I am always careful when such a switch has occurred not to try to go back to the deeper work. However, when I have been invited to work with a group and I do not undertake the deeper work, the person who has invited me can feel let down in some way. It is, therefore, worth discussing with them in advance about how the group might progress is deeper and more reflective work is not able to be tolerated.

8.1 Narrative

8.1.1 Action

Ask members of the group to write without stopping for 5 min on a theme that you have chosen in advance. Hint: sometimes I read out a newspaper story about an event, or I read one of my own narrative pieces; see for example, <http://bit.ly/2aNCNgk>; I always consider whether there might be any vulnerability within the group. If I have not met the group before, I try to choose a *safe* topic remembering that the first time I meet a group, I will have no idea what creates safety, and what increases their sense of threat and fear.

As leader, be observant of the group as they write and encourage individual participants to keep writing if they stop – NB: I do this gently in mime so as not to disturb the other writers. At the end of the period, ask them to share with the person beside them, and if they feel they are able to read out the piece they have just written, then ask for volunteers to read out their work to the class.

8.1.2 Reflection

Ask the group to reflect on what, in their opinion, writing in this way offered that just talking about it would not have done. What did it feel like to share? Were there any parts that were surprising?

8.2 Poetry

8.2.1 Action

Depending on the experience of the group, either use existing poetry to encourage reflection and further poetry or narrative writing or present a topic, encourage discussion and ask the group members to write a poem in response. Sometimes, I have introduced the Japanese poetry form *haiku* and encouraged group members to use the form to write a poem on the topic.

8.2.2 Reflection

Encourage the group to reflect on one poem they experienced as highly charged in some way – emotionally, viscerally, or through memory. They can do this in small groups, in discuss as a larger group, or through further writing.

8.3 Visual

8.3.1 Action

Bring multiple copies of magazines of all types – sport, fashion, travel. Ask participants in groups to create a montage using cut outs from the magazines that reflects a feeling or idea, or a contemporary issue (for example, climate change or the refugee crisis).

8.3.2 Reflection

Ask the groups to present their montage to the larger group. Encourage discussion of the challenging aspects of presenting the topic visually. What did the group learn? How was the process of cooperating in the task together?

9 Conclusion and Future Directions

Elsewhere, I have pointed to the current freedoms enjoyed in ABR (McCaffrey and Edwards 2015). Although there are a relatively low number of reports of research studies conducted through ABR in health, the advantage of the developing and

evolving nature of this space is that those of us championing the approach have the luxury of a wide remit; we can choose or develop methods and approaches that are unbounded by conventions and disciplinary or dogmatic regulations. However, this does not mean that laxity is part of the process. The main requirement of reporting qualitative studies is that the process by which the materials were generated and analyzed is clearly explained. In ABR, this can be a challenge as creative processes are not always linear or clear cut. Using a journal to keep track of developments in the research process and to document the steps in analysis can be useful.

One of the claims across many who research using ABR methods is the ability of arts outcomes to reach wider audiences than other types of research (Chilton and Leavy 2014). However, this claim has not been formally tested. Researchers reporting ABR studies are, therefore, encouraged to include the data regarding audience participation. For example, if the work has resulted in a play, the author/s should describe the number of shows and audience numbers for each performance. Additionally, it may be useful to describe the audience demographic details where these are sought during the research process or available by other means such as observation and description of the audience.

As ABR increases scope and impact, researchers, audiences, and participants will have valuable opportunities to reflect on insights gained and potential for further development. Within ABR, descriptions of unique approaches such as Creative Insight Method allow contemplation, testing, and elaboration to further the utility of techniques within the approach. Scholars at any level are encouraged to be courageous and excited at the opportunities that can be offered through Art-Based Research.

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Understanding Health Through a Different Lens: Photovoice Method

65

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Contents

1	Introduction	1148
2	Photovoice Procedures	1150
3	Photovoice Data Analysis	1151
4	Project 1: <i>Picturing New Possibilities</i>	1152
4.1	Project Summary	1152
4.2	Key Results: Visual Transformations of Self-Acceptance	1152
4.3	Implications of Findings for Practice	1154
5	Project 2: <i>The Snapshots Project</i>	1155
5.1	Project Summary	1155
5.2	Key Results: Impact of Posters on Viewers	1155
5.3	Implications of Findings for Practice	1158
6	Project 3: <i>A Picture Is Worth 1,000 Words</i>	1158
6.1	Project Summary	1158
6.2	Key Results: Growing up, Facing Loss, and Finding Strength	1159
6.3	Implications of Findings for Practice	1161
7	Discussion	1161
8	Methodological Challenges	1162
9	Conclusion and Future Directions	1164
	References	1164

Abstract

This chapter describes the application of photovoice, a method that enables people to identify, share, and address their lived experiences with photographs and discussions, to HIV/AIDS and Autism Spectrum Disorder (ASD) research. The use of photovoice has expanded tremendously over the last decade. The case studies in this chapter highlight the varied and important methodological uses

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of photovoice in public health. The cases feature photovoice projects that facilitate women with HIV's expression of their illness narratives, youth with ASD's accounts of growing up, and HIV patients' stories of medication adherence. Although the photovoice methodology varied slightly in each case, each project included: (1) introduction and camera tutorial, (2) group photo sharing and discussion sessions, (3) individual photo reflection interviews, and (4) public photo sharing. Theme and story analysis of project session transcripts and photographs revealed projects' process and outcomes. Across each case example, photovoice proved to be versatile and adaptable to different participants' needs. Photos enhanced dialogue by giving participants a way to creatively and concretely express themselves and share their ideas. The method served as a way to collect data, but also as an enjoyable and empowering process for participants with HIV and ASD. Photovoice also supported individual and group development and action such as increased self-awareness and education for picture viewers. Photovoice can be a powerful method for vulnerable populations. Care must be taken to match the method to research questions and participants' needs, create effective collaborations between researchers and participants, and attend to project ethics.

Keywords

Autism · HIV/AIDS · Photovoice · Public health · Qualitative · Visual research methods

1 Introduction

Visual artistic methods are common tools of health research and practice (Fraser and Al Sayah 2011). Public health researchers have capitalized on the benefits of photography, in particular, as a way to understand health issues from the perspectives of those living with health challenges, inform health interventions, and engage community members in identifying and solving health problems (Catalani and Minkler 2010; Fraser and Al Sayah 2011; Switzer et al. 2015). Although photography has been used in various ways in health research, this chapter focuses on the application of photovoice to HIV/AIDS and Autism Spectrum Disorder research and practice.

Photovoice is a research method that enables people to identify, share, and address their lived experiences with photographs and discussions (Wang 1999). The use of photovoice in public health originated with Wang and her colleagues' efforts to understand the everyday health experiences of Chinese women through participant-generated images (Wang 1999; Wang and Burris 1994, 1997; Wang et al. 2004; Wang and Pies 2004). Wang and colleagues described three goals of using photovoice – to enable participants to record their community strengths, to promote critical dialogue and knowledge about personal and community issues through the discussion of images, and to reach policy makers via these images (Wang 1999). The photovoice method relies on the ability of an image to act as a concrete starting point for shared conversations and interpretations, draw attention, motivate dialogue, and

present stories across diverse levels of participant language and literacy (Wang and Burris 1994; Wang 1999; Hergenrather et al. 2009).

The theoretical basis of photovoice includes three related concepts: empowerment education for critical consciousness, feminist theory, and documentary photography. These foundations share common assumptions about the importance of participants' voices (Wang and Burris 1994). Through focusing on and portraying participants' experiences, photovoice empowers individuals to understand and critically discuss the contextual issues that affect their health and well-being. This approach of collecting knowledge that is grounded in experience enables participants to collectively communicate their shared concerns/needs/vision to each other and to those with authority to allocate resources towards creating needed change (Wang and Burris 1994, 1997). From a feminist approach, photovoice promotes the value of women's and other unrepresented groups' experiences. Photovoice fosters conditions in which underrepresented groups are able to influence action (Wang and Burris 1994, 1997). Finally, in contrast to conventional documentary photography, photovoice puts cameras in the hands of participants (not professional photographers) and trains them to capture and use their own experiences to gain insights about their lives and inform decision-making processes in their communities. When project participants record their lived experiences and tell their stories, they are "often imaginative and observant" in ways that provide more richness to the data (Wang and Burris 1994, p. 177). Original photovoice methods (via Wang and colleagues) included a set of procedures to both gather data and translate research findings into action and practice. As a first step, projects included the identification of both a target audience – who could help put participants' ideas into action – and a group of interested photo-takers. Participants would then undergo a camera tutorial, a photo-ethics training, and an introduction to the photovoice method. A cycle of photo taking, discussion, and sharing followed. Discussions were guided by the "SHOWeD technique": What do you **S**ee here? What is really **H**appening here? How does this relate to **O**ur lives? **W**hy does the situation or concern exist? What can we **D**o about it? The facilitators and participants then worked together to share their photos and stories with policy makers via slide shows or exhibits (Wang 1999).

To highlight the varied and important methodological uses of photovoice in public health, we summarize the key aspects of three case studies in detail below. Although the study methodology varies slightly based on participant needs, several core components were consistent across the projects. These are outlined in Table 1. The use of photovoice in public health has expanded tremendously since its early applications. Numerous reviews (Riley and Manias 2004; Hergenrather et al. 2009; Catalani and Minkler 2010; Martin et al. 2010; Lal et al. 2012; Sanon et al. 2014; Han and Oliffe 2015; Switzer et al. 2015) document the expansive use of Photovoice and its application to women's health, chronic illness, mental health, and health disparities, among other public health topic areas (Riley and Manias 2004; Hergenrather et al. 2009; Catalani and Minkler 2010; Martin et al. 2010; Lal et al. 2012; Sanon et al. 2014; Han and Oliffe 2015; Switzer et al. 2015). Across diverse applications, the end goals of photovoice have centered largely on the understanding of health needs, challenges, and assets; health action and advocacy; individual and

Table 1 Project Descriptions

Project	Participants	Goal	Dissemination	Main results
Picturing new possibilities	30 women with HIV	Participants: tell story of HIV	Exhibits at local HIV community events	Participant experiences: empowerment, social support, way to communicate health transformations, help with HIV stigma
		Researchers: understand impact of photovoice on participants		
Snapshots	16 people with HIV	Participants: capture medication adherence challenges and motivators	Posters in HIV clinic	Patients who viewed the posters described them as comforting, relatable, inspiring, and as creating a culture of caring in the clinic
		Researchers: explore how disseminated photos affect other patients' adherence practices		
A picture's worth 1,000 words	11 young adults with autism	Participants: express transition to adulthood	Exhibit in autism center	Youth expressed meaning of adulthood, need for independence, employment desires
		Researchers: understand youth's priorities and service needs		

community empowerment; and health intervention (Catalani and Minkler 2010). The original steps of the process have been modified by researchers to adapt to specific participant needs and research goals. For instance, Switzer et al. (2015) adapted their photovoice project with drug users to accommodate participants' concerns about confidentiality, completing individual interviews with participants, and forgoing group discussions.

2 Photovoice Procedures

Each project included four major components: (1) project introduction and camera tutorial, (2) two group photo sharing and discussion sessions, (3) individual photo reflection interviews, and (4) public photo sharing. Introductory and photo discussion sessions were facilitated by one to two trained facilitators (including the first and third authors). The facilitators delivered the sessions to participants in small groups of four to eight. Participants attended the sessions weekly over the course of 1 month. During the first session, the facilitator explained the purpose of the project and the participants brainstormed different potential ideas for photographs and discussed the ethics of picture taking (Teti et al. 2012). For instance, participants identified appropriate and inappropriate photographs (e.g., illegal, unsafe), how to obtain consent to photograph another person, and how and where to access support

for issues raised in the taking and discussing of photographs. At the end of the first session, each participant received a digital camera to keep and practiced basic camera functions (e.g., on, off, shoot, save, edit, zoom).

During the second and third meetings, the participants reconvened to review and discuss their photographs. The facilitator led these discussions with a laptop computer to download and display photos via a projector. Each participant presented several (range 2–10) photos of his/her choice to the group and discussed what each photo meant. We facilitated these discussions using a semi-structured guide that helped participants to express themselves. Sample questions included: “What does this photo capture about your life or story with [illness]?” and “What does the picture or issue mean to you?” and “What challenges or strengths does the image convey?” After each participant presented and discussed his or her photos, the group responded to the images.

During each session, participants discussed and brainstormed opportunities to share their photos with others in their families or communities. The facilitators finalized exhibit planning. As part of the third session, participants chose photos for review and helped to develop or edit captions for the photos. Each participant presented one to three photos of their choice at public exhibits or public displays (see Table 1).

Following the exhibit, photovoice project staff (including the first and third authors) conducted 1 h individual-level interviews with each participant to explore his or her experience in the project and give participants a chance to reflect on their pictures individually. Example questions were: “What did you learn about yourself in the process?” and “How did you decide what to photograph?” and “What was it like to share your pictures with others?” All participants were compensated monetarily for their time in the project sessions. We digitally recorded each group and individual intervention session to capture data for analysis.

3 Photovoice Data Analysis

Project data included photographs and group and individual interview transcripts. We transcribed the interviews verbatim and analyzed them using Atlas.ti (Scientific Software Development 2011), a qualitative software analysis package. To analyze the data, we employed a mix of theme (Boyatzis 1998) and narrative/story (Riessman 1993) analysis – a common strategy used in public health research with vulnerable and complex populations whose data transcripts reveal rich concepts that need to be understood in the context of their overall stories (Rich and Grey 2005; see also ► Chap. 48, “Thematic Analysis” and ► 49, “Narrative Analysis”).

First, we analyzed the data for key themes (Boyatzis 1998). Two researchers reviewed the transcripts and photos multiple times to become familiar with the data and key themes. We created a codebook describing the most salient themes of interest and analyzed the data via coding and analytical memos (Boyatzis 1998; Charmaz 2006). Coding matched text to themes and progressed in two stages, open or more general coding – which included coding for broad codes, which was followed by selective or more specific coding which broke down the broad codes

into more detailed concepts. Selective coding resulted in the final themes presented in the results (Charmaz 2006). We wrote analytical notes throughout all phases of coding to highlight key questions about relationships in the data and to refine codes. After coding the data, we generated coding reports that collated the evidence for each theme.

Comments about themes often occurred within participants' stories. To ensure that we understood the themes with the context of these larger narratives, we also constructed a narrative table for each participant (Riessman 1993). Each narrative table summarized each participants' overall story conveyed in both the group and individual sessions in a linear fashion (e.g., was diagnosed in 2005, had to quit job, struggles with stigma, is still fearful about illness but feels healthy, etc.) and included a list of pictures that elaborated on specific aspects of the overall story. Then we drafted and revised the results section using the theme coding reports and the narrative table to ensure proper context of the thematic examples.

4 Project 1: *Picturing New Possibilities*

4.1 Project Summary

Picturing New Possibilities was implemented to meet HIV-positive women's expressed need for more opportunities to share their stories of HIV and relate those stories to their health (Teti et al. 2010). Thus, the goal of the project was for women to tell their stories of HIV through photovoice. The research questions driving the project were "What stories do women tell through photovoice?" and "How does photovoice support or affect women's story-telling process?" Participants included 30 women, recruited from HIV clinics and AIDS Service Organizations. The majority of the participants were poor. Over half ($n = 18$) of the women reported earning less than \$10,000 a year. Most of the participants identified their race/ethnicity as Black ($n = 25$), three identified as White, and two as "Other." On average, the participants were living with HIV for 11 years (6 months to 17 years).

Analysis of the data indicated that one of the key ways that photovoice supported women was to give them a way to visually demonstrate various positive transformations in their lives. There is no doubt that women with HIV face various challenges. Popular media and scientific research generally dwell on these challenges (e.g., women with HIV as sick, poor, down and out, struggling). Photovoice offered women a way to define themselves differently. With concrete images women shared positive changes in their lives, including their journey to self-acceptance with HIV.

4.2 Key Results: Visual Transformations of Self-Acceptance

Women presented visual analogies of reaching a point where they: accepted their diagnosis, believed that they could live with or survive HIV, created a life and an identity *beyond* HIV, and took control over managing HIV stigma. For instance, a

participant who had HIV for 17 years said she initially had an “internal stigma” and could not accept that she had HIV. She said she “kept [having HIV] inside of me for so many years and then finally, I [decided], I’m going to talk out about it, and when I talked out about it, I felt liberated, I was free.” Sharing a picture of her face, she said she became “comfortable with [HIV] in [her] own skin.” She said she learned to “accept HIV for what it is” and describes herself as a different person:

I’ve chosen not to be ashamed in my life. . . I’m free to be whoever I want to be. I tell people, “I’m grateful for [HIV]. I truly am.” It’s like living a whole new life. . . HIV really made me know who I was overall. . . I believe that HIV has freed me to be.

For other women, acceptance of their HIV meant recognizing that they wanted to share their life with HIV with others more openly. For instance, one participant said that through her pictures she showed that she “is strong enough to let everybody know what’s going on with me in my life and that I have HIV. I’m not in the closet about it.” She said when she showed others her pictures, “I was pulling people to look – ‘Look at me. Look at me.’” Similarly, another woman shared a picture of her in the newspaper and said “That picture means the struggle’s over and I don’t have a problem putting my name to nothing. I came a long way.”

Sometimes reaching a point of acceptance with HIV meant making peace with the struggle. Living with HIV for 8 years, another woman described how she wanted to tell other people about her HIV status, but “wasn’t there yet.” To explain this visually, she shared a photograph of wires, tangled and attempting to connect with each other (see Fig. 1). She said she was taking baby steps though. She shared several pictures, including this flower growing out of a rock (Fig. 2), to explain that with her art work and her life with HIV, she “created something new with something that had died,” and that she was looking forward to “growth” and how “life will find a way” despite HIV and HIV stigma.

Still other women portrayed their transformation to HIV acceptance with visual representations of the realization that they wanted to focus less on HIV in their life.

Fig. 1 Wires demonstrate how the participant feels disconnected and confused about sharing her HIV status with others

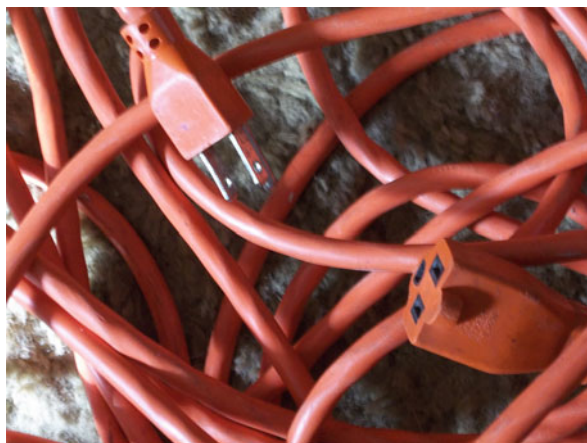


Fig. 2 Growth exemplifies that the participant is looking forward to sharing her HIV status



One participant explained that she wanted to continue to take pictures to capture new beginnings in her life – like her school. She said, “I’m not HIV anymore. It’s not ‘my everything.’ It is part of me and it’s becoming kind of more in the background of my life.” Another noted, as she shared a photo of the city that she lived in, that her transformation was becoming just “like everybody else.”

I don’t think about my HIV when I’m walking down the street or when I’m talking to somebody, “Do they know I got it, or they scared to shake my hand?” I’m just a person like everyone else in the world, trying to survive – who’s going to survive. HIV – it don’t have me. I got it, but it’s working with me.

HIV prompted all of the participants to consider their lives with HIV in new ways. Although acceptance of HIV was different for everyone – some women moved or made steps to move out of HIV-related denial and secrecy, other women learned strategies to confront stigma, and still others expressed a desire to move beyond HIV – reaching their version of acceptance was an important transformation in women’s lives, particularly given the barriers that denial, secrecy, and stigma can pose to women living with HIV and their mental, physical, and social health. Through using new ways of expression and open dialogue, photovoice supported women’s presentation of this experience.

4.3 Implications of Findings for Practice

All of the participants could recognize positive changes and transformations and all of them said that they were rewarded by this process. Their stories of transformation also

highlighted the lack of spaces for women with HIV to talk about positive aspects of their lives, such as their efforts and journey to accept HIV. Health programs and interventions also tend to unintentionally discount women's positive experiences. HIV interventions, for example, typically help people at risk for and living with HIV address what they may be doing wrong – like having unsafe sex or failing to take medications, versus helping them to build what they do right (Herrick et al. 2011, 2014). This is important and understandable because these behavior changes are paramount to the health of women and their partners and because the challenges women face to living healthily – like poverty, discrimination, violence, and stigma – are so daunting. Our findings serve as a reminder to practitioners developing and implementing programs that women with HIV are not a monolithic group and experience successes as well as challenges (Goggin et al. 2001), and that women feel proud about these successes.

Understanding women's transformations may also be a potentially helpful way to understand women's motivation to make healthy behavior changes, such as safe sex, medication adherence, and engagement in HIV care. Meeting these goals can prolong WLH's lives and also help curb the spread of HIV to others. Behavior change, particularly change that needs to last over the life course, is difficult, complex, and hard to understand. *Picturing New Possibilities* provided a glimpse into women's experiences of making notable changes in their lives.

5 Project 2: The Snapshots Project

5.1 Project Summary

Snapshots was implemented to improve medication adherence among people living with HIV. A small sample of people living with HIV used photovoice to share how they experienced life with HIV, managed consistent adherence to their HIV medications, and problem-solved medication-related challenges. They used these photos and stories to create ten different medication themed posters (versus a “traditional” photovoice exhibit). The posters were then displayed in the participants' HIV clinic to help improve adherence attitudes and communication with health care providers about adherence. The research questions driving the analysis of this project were “What stories do participants tell about medication adherence?” “How does using photovoice to create the posters affect participants?” “How does viewing the posters created through photovoice affect the viewers?” Photovoice participants, who made the posters, included 17 people with HIV, 10 of whom were women. The majority of participants were poor, over half reporting earning less than \$10,000 a year. Ten participants were Black and seven were White. On average the participants were living with HIV for 13 years (range 3–33 years).

5.2 Key Results: Impact of Posters on Viewers

Three key themes in photovoice participants' images and discussions captured their motivations to become and remain adherence including important people or things,

YOU CAN LIVE

People will throw stones in your path. It's up to you to build something with them. You are the builder of your life.

Reality hits when you walk into the clinic. You have to face HIV. I understand - I cried for three years, but I don't want anyone else to waste three years. I want people to know it's important to keep their appointments and take their medications exactly as prescribed. Taking my HIV medications and remaining adherent for seventeen years has been a life saver for me. Living with HIV starts with, well, *living*. It can be rough, but that's expected, so is life. I let people know, "You can do this. You are going to be ok. We can do this."

This is what I used to take in one day: 8 pills in the morning, 8 more at lunchtime, and the last ten at bed. I used to cry looking at them. Over the last seventeen years, I've watched my medication go down to one pill a day. I feel like I'm winning this.

MY MEDICATIONS HAVE HELPED ME MAINTAIN A STABLE AND HAPPY LIFE

SNAP SHOTS
TMC
TRIUMPH MEDICAL CENTERS
Better. For Everyone.

If you are feeling down and out of place, talk to your peer or a provider today. We are here to listen and help you feel better in any way we can. All people with HIV can live long and healthy lives, especially if they come to their appointments, take their medicines, and get help when they need it. Photos and quotes were collected for the *SnapShots Project*, which gave HIV positive patients the opportunity to creatively share their stories.

Fig. 3 Poster example – hung in clinic to inspire others with HIV

symbols of hopefulness about the future, and adherence as a way to take control over one's health. Example images corresponding to these themes included medication routines, support systems, pets, self-portraits, and nature. The research team and the participants worked together to create posters that showcased these themes (Figs. 3 and 4). Our primary analysis question focused on understanding how the posters affected the viewers who saw them. Participants told us that the posters were powerful because they were relatable and also because they helped to



Fig. 4 Poster example – hung in clinic to inspire others with HIV

create a culture of caring in the clinic. For instance, one viewer noted, “I was inspired, touched. I felt and saw me in these pictures [on posters] – I could relate [to them].” Another viewer called the posters “comforting.” Others commented on the benefit of seeing other’s faces, saying, “They’ll get your attention, especially when you start seeing faces” and that the posters were helpful because “Each one of these posters is different, you can see a little bit of each person’s life inside these pictures.”

Other viewers appreciated the posters' value for the clinic overall. One viewer noted, "[The posters] let me know that the providers are willing to showcase what people are going through because sometimes when you come to the clinic you have people scared." Another called the posters "poems in the entrance area" of the clinic. Several viewers remarked that the posters would be important for others to see, especially newly diagnosed patients. For example, one viewer said:

If they had these in the rooms while we're sitting back and waiting, I can just see that person who's very fearful, and scared. . . Being alone in the room while you're waiting, we do stare at the walls. This can be artwork for the doctor's offices where people can relate. They're powerful. This here is us. My doctor goes home every day. My doctor doesn't have to take a regimen. This here will talk to you in a different way than what our providers can teach us. This is real. This is someone who understands, and knows, and deals with it.

5.3 Implications of Findings for Practice

Snapshots findings suggested that patients appreciate education materials that are relatable and easy to understand. They like seeing other people like themselves, and hearing other stories like their own stories, on educational materials. These findings support a growing body of research that stories and narratives are more effective than didactic information in promoting both health education (Jibaja-Weiss et al. 2006) and health behavior change (Houston et al. 2011a, b; Murphy et al. 2013, 2015). In the *Snapshots* study, stories helped viewers with HIV to feel comforted and supported. The posters themselves reinforced, via the images of real people with HIV, that if they take their medicines regularly they will be okay. Thus, our findings suggest that these posters can improve confidence towards taking medicine. Seeing the posters in the clinic also sent a message that the clinic cares about people with HIV, the stories of people with HIV, and in creating an open dialogue about those stories. This indeed could improve communication between patients and providers. Harnessing photovoice to capture the stories and images of people with HIV can lead to the development of easy to understand, accessible, and powerful health education materials.

6 Project 3: A Picture Is Worth 1,000 Words

6.1 Project Summary

Youth with autism spectrum disorder (ASD) experience great difficulty in the transition to adulthood. Most research on youth's transition focus on poor achievement like low college graduate and employment rates (Shattuck et al. 2012). There is a paucity of research on how youth with ASD experience this time in their lives and navigate and address challenges. In this project, 11 youth with ASD used photovoice to express their experiences of becoming adults. Youth with ASD are particularly

challenged by this transition due to their increased dependence on their families, need for repetition and consistent schedules, and difficulty in establishing and maintaining friendships (Cheak-Zamora and Teti 2014). Although the disorder affects each individual in different ways, the combination of comorbid physical conditions, mental health deficits, and developmental disability makes transition into adult life difficult for all youth with ASD (Beresford et al. 2013). Given that many youth with ASD also face challenges communicating their opinions, feelings, and needs to other people, the purpose of this project was to use photovoice to facilitate concrete communication and discussion of youth's priorities. The mean age of the sample for this project was 20 years (range 18–23 years), 64% of the participants were male, and 91% were Caucasian. Four of the 11 (36%) participants were in high school, 3 (27%) were in college, and 4 (36%) were not in school at the time of the study. Although we did not specifically measure functioning level, 27% of the participants required assistance to complete the demographic survey, which may suggest lower functioning.

6.2 Key Results: Growing up, Facing Loss, and Finding Strength

The youth mainly described adulthood in terms of “accepting responsibilities.” One youth stated “[by assuming] certain responsibilities [one] would infinitely detach you from being described as a kid.” Examples of images that youth used to help them explain adulthood and what responsibility meant to them included pictures of a money saving system in which the youth separated money into different jars, and a picture of a youth taking on the responsibility of exercising at the gym. The latter picture stressing specifically that youth with ASD may interpret responsibility in nontraditional ways, which could be hard to explain verbally.

Pictures and discussions of adulthood also focused on jobs – since youth were also concerned with living on their own and “moving out of the nest.” Although the majority of youth were employed at the time of the study ($n = 7$), they expressed dissatisfaction with these experiences. Several youth remarked or hinted that they believed they had more skills and potential than working in janitorial services, a common place of youth employment. For example, one youth who disliked his job as a janitor stated that he wished he could “stop cleaning up crap” and “[does not] want to be there [at work] sometimes.” When describing one of his pictures, a youth said that his facial expression conveys, “Get me out of this building. I don’t want to work here anymore. . . . I don’t want to work there anymore.” As opposed to their current jobs, many of the youth described their ideal job as “being an author” or “thinking about becoming a veterinarian.” One youth took a picture of a bird he was taking care of in order to explain his love of exotic animals and drive to become a veterinarian. Jobs represented a route to independent living, socialization, and a new burgeoning identity.

Unfortunately, youth also associated growing up with experiences of loss. Multiple youth noted that they felt sad due to losing a loved one. Roger lost a grandfather shortly before the study, when asked about how this affected him, he stated, “It’s



Fig. 5 Table representing Grandfather's life and death

weird because it just feels like a piece missing.” He also took a picture that represents his feelings surrounding losing his grandfather (Fig. 5):

This [picture] is the table with the last memory of seeing my grandfather alive, and he passed away this October (date). . . . And I’m sitting where he was sitting and just remembered that I took him that day. . . . [I talked to] my mom, my grandma [about my grandfather’s death], and it’s weird because my aunt’s husband’s father passed away the week before my grandfather died. That Thursday after the (date), my grandpa’s sister died from cancer. So it was a very [depressed] couple of weeks and drained a lot of energy out of us, but we made it.”

Laura used pictures to explain that she experienced both sadness and anxiety around her grandmother’s death. She experienced stress over her grandmother’s house, saying that, “I’m just worried about that house, her house. I really love that house. I don’t want any stranger living in that or changing it. I just want maybe a relative might stay. . . , just to keep it safe.” Several youth talked about sadness related to losing a pet, sharing pictures of the animals to express their grief.

Youth also explained that showing their lives through pictures allowed them to view ASD as a special experience, and not just a challenge. One youth noted people with autism are “gifted.” Through photographs the youth highlighted some of the positive characteristics, abilities that individuals with ASD possess, and how they were “defying the label.” For example, one youth took photographs of sporting events to show that she engages in social activities, another youth photographed his teacher to represent “the progress I’m making to better myself,” and yet another showed a photo-shopped picture of himself shooting an apple off of his own head. Highlighting that he is a “very artistic person,” one youth stated that people with ASD are “very detailed” and thereby could capture detailed pictures that others could learn from or enjoying viewing.

6.3 Implications of Findings for Practice

Health care and service providers who work with youth with ASD want to provide good care, but it can be difficult to understand and meet youth's needs. Photovoice may offer youth and those who care for them an alternate way to communicate. Further it helped youth get passed the surface (rote answers) that they generally provide to alternatively describe what they really needed and wanted in their live. Our findings suggest that youth were able to explain themselves and even their emotions through images. They were confident when explaining their pictures and took pride in sharing their views and thoughts. Integrating photovoice into medical services, for example, could allow youth to create images to form a bridge to communicate with providers and help to form their care plans. Social and employment support services could also gain from photovoice endeavors that give youth a chance to express how they feel about their social situations, what they want from work, and their personal goals. The camera and the pictures also allowed youth to express some of the positive aspects of their lives, which could otherwise go unnoticed. Thus, photo-stories could also serve as a way for youth to demonstrate and celebrate their strengths more confidently than they may be able to do than with words alone.

7 Discussion

In this chapter, we have presented three different applications of photovoice in public health. Although the projects included different populations and had different goals, each project used the same basic photovoice process. Similarities across the projects shed light on some of the most important aspects of the method.

Photovoice is versatile. Original applications of the method included a structured set of procedures (Wang and Burris 1994) which have been adapted or used to varying degrees over time. Given that one of the key tenets of photovoice is its focus on participants' experiences, it is logical that the method should adapt to meet participants' needs. However, our work confirms that the method does include several core concepts. Fundamentally, the method includes photos as catalysts for identifying and describing experiences, reflecting on experiences, and sharing those with others. Photos contribute more than words alone. For example, in Project 2 (*Snapshots* – men and women with HIV), the photos (e.g., “familiar faces”) were what captured viewers' attention and helped them to relate to HIV medication adherence messages. In Project 3, participants with ASD may not have been able to express themselves as clearly without the assistance of photos. Photos help participants to be concrete, to see their environment in new ways – or to see new things in their everyday surroundings – and to reflect on their experiences in different ways than through words alone.

Secondly, photo-sharing is essential for group dialogue, which can enhance both individual's and groups' ability to identify and solve problems or difficult scenarios that evolve through the photos. The photo provides a shared vision or a starting point

for conversation. In each project, the participants shared their photos with a group and one-on-one with a facilitator. By sharing, participants were able to discuss different meanings in the images and further create their stories. In project 1, for example, each HIV-positive woman's journey was complex. By sharing it they were able to make sense of it, identify similarities with others, and problem-solve challenges that arose, such as how to manage HIV stigma. Within project 3, youth with ASD were able gain understanding of others that they hadn't prior, "I think just hearing everybody else's stories. . .It was nice to hear, you know, people like me, what they're dealing with and how they operated." Photovoice is thus particularly relevant for vulnerable groups of people who often face stigma or misunderstandings about their illness. This is true in the case of both HIV and Autism, despite the fact that they are very different health experiences.

Third, as a participatory method, photovoice is a data collection tool that can enhance participants' lives. In project 1, for example, the researchers gathered important data about the implications of women's transformation experiences for HIV interventions. Women themselves benefitted from telling these stories and capturing their positive transformations. In project 2, the research team was able to design and test educational posters using the results of photovoice. Participants themselves were able to share their challenges and successes, which they reported helped them to make important reflections and help others. In project 3, the researchers learned about the transition needs of youth with ASD that they previously were unable to communicate with their families. Youth were able to express themselves, and like women with HIV, they were able to access positive parts of their experiences in particular through photos.

Lastly, photovoice is about action. Such action can take different forms, however. Women with HIV in project 1, for example, took action by redefining themselves as capable of making positive life changes with HIV. Men and women with HIV in project 2 embodied action by turning their stories into ways to educate other people with HIV. For youth with Autism in project 3, action was being able to more clearly and confidently express themselves.

8 Methodological Challenges

Photovoice does pose methodological challenges. Photovoice projects are only appropriate for participants who are interested in the method and able to express themselves with pictures. This means that participants need to be willing to take pictures, disclose their identity to a small group, self-identify with their illness (i.e., not be in denial about having HIV, for example), and be willing to share their illness experiences publically via exhibits. They also need to be able to operate a camera and use it to talk about their health. All of these tasks can be daunting, especially when the method is used with populations who may face stigma or misunderstanding or with underserved populations who may be uncomfortable with learning new things and with opening up to "strangers."

Photovoice results in complex data in multiple forms, like text and images, or individual and group-based discussion data. Thus, the data are timely to analyze and data transcription can be costly. These types of data are obviously suited to qualitative analysis. While the identification of qualitative themes is helpful, it is usually hard to make any comparisons or associations qualitatively and with a small sample. When examining the impact of the process on participants, it is hard to distinguish the effects of different aspects of the process on participants, like taking pictures versus discussing pictures versus exhibiting pictures. Experiences that participants do report as resulting from the projects, such as “empowerment” are also generally broad and multifaceted.

Ethical concerns arise when using photographs as data as well. Participants may take or want to take pictures of themselves or others in compromising positions. Similarly, participants are challenged to explain the project and seek consent if they want to include others in their pictures. If participants engage in illegal or unsafe activities as part of their illness experiences (e.g., drugs and alcohol), they must find ways to safely capture and portray these experiences to others. Participants may fear disclosure of themselves with their illness as their images are shared via exhibits. Additionally, both participants and researchers need to decide on fair rules for photo dissemination. Academic standards for publications such as the use of pseudonyms may not make sense to participants who want to take ownership over their work, for example.

The continued and growing use of technology may also change the future of photo projects and complicate ethical and other project procedures. People of all income levels now routinely have phones. These phones, however, may take pictures of varied quality. To ensure that all photos can be used a process may be necessary to standardize the photographs. Social media platforms such as Facebook or Instagram that rely on photos, or phone apps, may be logical places to integrate photovoice. The more immediate and more widespread sharing of photos may indeed require enhanced ethical protections for participants.

Despite these limitations, we believe that photovoice is an excellent way to collect nuanced information about health experiences. Based upon the results of the projects described in this chapter, we recommend the following for using photovoice successfully:

- Before beginning a photovoice project, decide if photovoice is the right method for the research question at hand. Photovoice is best suited for exploratory research questions and for use with marginalized populations who may have lacked access to expressing their needs historically.
- Determine how photos will add value to the data collection and participant experience. How will the research question be more deeply answered by the photos? How will participants express themselves differently via photos than with words alone?
- Photovoice is meant to be a partnership. Participants will drive the data collection with their photos and discussions and the data, in turn, will benefit research. The goals of the project and the pros and cons for each group should be obvious and

apparent before the project starts. Determine ways for participants to view and member check the data before it is exhibited.

- Ensure that the project is properly budgeted for and staffed. Will participants use their own cameras? How will participants be compensated for their time? Where will the exhibit take place? What is the purpose of the exhibit?
- Ethical guidelines and expectations need to be established at the project start. At a minimum, these need to include plans for taking picture of others, private and illegal activity, disclosure, and photo ownership. Support systems for participants should be in place if the process brings up issues that require further assistance or steps for action.
- The design process should allow for flexibility. The purpose of photovoice is to adapt to participant needs and give them a way to identify, express, and prioritize their needs. Although original photovoice projects had very specific protocols, participant needs, such as to participate in one on one versus group discussions, should be honored above following a strict protocol.
- The ways that technology can assist the process should be considered and tried at participant request.

9 Conclusion and Future Directions

Photovoice is a flexible method that public health researchers can use to uncover rich data about participants' lived experiences of their health. These narratives can help us better align public health research and practice with people's lives and priorities. The method is also beneficial in that it can help participants gain skills and embrace confidence about their health stories. The core components of photovoice – images, group discussion, participant growth, and action – can be adapted to meet individual project and population needs. Although challenges to using Photovoice do exist, careful planning and project development can lead to insightful visions of participant's lives and health needs.

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IMAGINE: A Card-Based Discussion Method 66

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Contents

1	Introduction	1168
2	A Method as a Response to Three Major Challenges	1169
2.1	Rendering Nondebated Issues Accessible	1170
2.2	Participatory Justice	1170
2.3	Countering the Lay-Expert Divide	1170
3	IMAGINE: A Card-Based Discussion Method	1171
4	Creating the Cards and Deciding on Stages	1172
4.1	Exploring and Analyzing the Issue	1172
4.2	Card Types and Choreography	1174
4.3	Validating the Card Sets and Making Choices in the Choreography	1176
5	Conducting IMAGINE Discussion Groups	1177
5.1	Assignment of Turn-Taking	1178
5.2	Keep the Discussion Going	1178
5.3	Encourage Discussion Among Participants: Not with Moderator	1178
6	Analyzing IMAGINE	1179
7	Conclusion and Future Directions	1180
	References	1181

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Abstract

This chapter introduces IMAGINE – a card-based group discussion method for qualitative research and engagement processes. IMAGINE was developed as a response to three major challenges that tend to emerge in discussion groups and participatory exercises. First, it renders new or complex issues accessible by offering participants a broad repertoire of structured resources without pre-configuring the issue too much. Second, it seeks to contribute to participatory justice by assuring that all participants get time and space for expressing their visions. Third, the cards allow the introduction of expert opinions without expert presence, thus avoiding the emergence of strong lay-expert divides. The method consists of a number of different card sets and a specific choreography. We explain the rationale behind different card types and how researchers can go about creating their own card sets. The contribution also includes suggestions for how to conduct and analyze IMAGINE discussion groups so as to harness their full potential. It concludes by pointing towards potential future directions in which the method could be developed.

Keywords

Card-based discussion method · Group discussions · Deliberation · Engagement · Participation · Participatory justice

1 Introduction

Over the past decades, the use of discussion groups as a research method has resurged in the social sciences. Simultaneously, there have been numerous efforts to create new formats that hold the promise of being better adapted to explore and engage with new problem formations that emerge in relation to technological and scientific developments. Through rethinking engagement, they try to address the changing social fabric of contemporary societies, the diversified information infrastructures, as well as the shifting perceptions of how knowledge, values, and choices are or should be interrelated. These methodological innovations are of particular interest as they often cross the boundaries between academia and nonacademic environments, being used in multiple sites and for a broad range of purposes. In policy-related fields that deal with questions of science and technology governance and decision-making about public goods and (healthcare) services, for example, diverse forms of discussion and engagement methods, have become central to stimulate citizen, patient, or stakeholder engagement (Chilvers and Kearnes 2016).

The reasons for the development of such participatory processes and a broader engagement with the spectrum of positions held within diverse societal collectives are manifold (Stirling 2008). In an instrumental way, they are often perceived as means to build public trust in institutions and systems, which are fairly distant for most members of society, as well as to gain acceptance for

technoscientific or biomedical innovations. From a normative point of view, they are meant to constitute an essential and intrinsic part of a democratic society with openness, transparency, and plurality as its core values. Finally, including visions and values of various societal groups (e.g., patients, user groups, consumers, concerned citizens) may open up new perspectives on innovation as well as address relevant ethical and social issues that foster the design of more socially robust processes and products.

In order to realize these different goals, a range of discussion oriented participatory methods have been developed and applied, among them most prominently citizen juries, citizen panels, consensus conferences, or citizen advisory committees (Bowman and Hodge 2007; Delgado et al. 2011). These methods vary in structure, group composition, and output-orientation, but they all tend to share the ideal of making the discussion of technoscientific issues and/or decisions more inclusive, empowering, and deliberative. What such events of participation and engagement aim for, ranges from a clear statement towards the issue at stake (sometimes based on the analysis of present social scientists, sometimes written by participants themselves) to the wish for a deeper understanding of the interactive process itself and how positions in the group (can) emerge.

In this chapter, we present a *card-based group discussion method* (IMAGINE) whose development was driven by an STS (science and technology studies) understanding of social scientific methods as embodying a normative and performative power (Law 2004). By using different sets of cards for participants to work with, the method seeks to stimulate and support the process of developing imaginations with regard to emerging technoscientific and other complex social issues. IMAGINE aims to enhance the capacity to gradually assemble, in interaction with other participants, the elements or “building blocks” that are used to assess an issue and construct a position. Its core analytic interest is to investigate how people analyze and relate to specific matters of concern in the present and to their potential futures, i.e., how they think a specific part of “the world” works and how they imagine it might or should work in the future. The method can thus be used in two ways: (1) to inform policy or other decision-making authorities about the processes, resources, and value systems people, both individually and collectively, relate to and draw upon when developing a position towards a problem at stake; (2) to support social scientists in developing a more fine-grained understanding of processes of public imagination and assessment with regard to scientific, technological, or other complex and nascent issues in society.

2 A Method as a Response to Three Major Challenges

IMAGINE was developed as a response to three major challenges that we identified in observing discussion processes in participatory exercises (Felt and Fochler 2010) but also in performing public engagement exercises in the framework of research projects on nanotechnology (Felt et al. 2014, 2015) and biomedicine (Felt et al. 2008, 2009).

2.1 Rendering Nondebated Issues Accessible

The first challenge is related to the matter of concern at the core of the engagement exercise. Sometimes, we have to analyze and assess a development at a point in time when it is not yet widely present in the public arena. Then most participants lack broader frames of reference. They have no examples of how different relevant societal actors conceptualize and narrate what is at stake, and thus, have difficulties to develop and unfold their thinking beyond rather vague reflections. To counter this, we deliberately did not want to present ready-made scenarios (Bennett 2008; Türk 2008) to participants, as we think this might not sufficiently foster their own creative work. We, thus, needed to find a way to bring dispersed and often not easily accessible information (scientific, technological, social, political, and so on) and societal positions to the table. We decided to prepare different sets of cards, which participants could use as starting points for their thinking and deal with in a flexible manner.

2.2 Participatory Justice

If one works with heterogeneous groups – as it is often the case in public engagement initiatives – people with different backgrounds, agendas, relations to the topic, and knowledge forms (e.g., professional expertise, experiential knowledge of patients) will meet. Due to this diversity, the degree of participation may vary largely among participants and create a situation of participatory injustice. For instance, people with more experience in discussion settings or with higher education often find it easier to express their position than others who are not well acquainted with such situations. Thus, a central question in discussion groups is how to assure the inclusion of all participants and to create a space where a broad spectrum of positions could be expressed. This means both assuring moments in the process where everybody gets voice and offering support to express their views openly, even if it was a clear minority position.

2.3 Countering the Lay-Expert Divide

Research into participation processes with lay and expert interaction shows that the inclusion of experts may lead to lay participants being co-opted by and following expert framings (Kerr et al. 2007; Felt and Fochler 2010). This “stakeholder capture” effect (MacLean and Burgess 2010) reproduces the power of representatives from influential groups, who often have a privileged access to technological or scientific knowledge. In order to minimize this effect, we refrained from inviting experts and instead thought about alternative ways to bring expert opinions to the table.

These three concerns led to the development of a card-based discussion method we call IMAGINE (Felt et al. 2014), and which we describe and reflect on in the following sections.

3 IMAGINE: A Card-Based Discussion Method

The general aim of this card-facilitated discussion approach is to create a flexible space that takes shape through a series of individual choices (of a number of cards) and subsequent phases in which participants are encouraged to develop and negotiate individual and collective positions in a discussion. Several shorter and diverse inputs in the form of different sets of cards stimulate and guide this process.

Card-based methods have been used in both participatory settings and qualitative research. For instance, the PlayDecide card game (PlayDecide is based on the Democs cards, a card-based public engagement tool (see <http://www.playdecide.eu>, accessed 01 July 2016).) has been developed as a public engagement tool. It shares with IMAGINE the idea of providing distinct sets of cards, but its goal is neither research-oriented nor do the stages and cards follow the same logic: PlayDecide emphasizes the need to “inform” participants with the cards, and it often ends with a voting on several, predefined solutions/options. Cards have also been applied in focus group research to discuss sensitive issues (Chang et al. 2005; Sutton 2011) or to observe how people rank topics in a collective manner (Kitzinger 1994; Bloor et al. 2001). IMAGINE differs from these approaches in the following way: it is strongly process-oriented; card-choice is more individual as each participant has her/his own sets of cards and a board for “documenting” choices; it does not aim at information or decision-making. Furthermore, IMAGINE does not solely encourage participants to assess the issue at stake at present (and reflect on past developments), but to also engage in imagining where a specific development might lead to and how this future potential might impact present choices. The method should, thus, trigger the imagination of participants of where we stand in a development and where it might lead us, i.e., embed a temporal dimension in their reflection. We consider imagination here as a productive cognitive but also social process that includes both retrospective and prospective dimensions (for a summary of research on imaginaries see McNeil et al. 2017).

We now want to briefly describe the central elements of the method. IMAGINE follows a multistage choreography, which consists mostly of three to four stages. Each stage sheds light on the matter of concern from a different perspective, lasts approximately the same length (in our case 45 min), and comes with a specific set of cards (see next section for more on card types and stages). This choreography provides a clear structure without predefining or restricting what can be discussed, invites to shift perspective, and allows some moments of individual reflection when choosing the cards for the respective next stages. A discussion group would in our case last for approximately four hours (including a break), which is about twice as long as traditional focus groups. This length is feasible because the method alternates between more active discussion phases and moments in which the participants read and choose new cards in a silent manner. This process allows refocusing their attention, to rethink the discussion process so far, and decide where they would like to take it in the next stage.

IMAGINE was originally designed for around *six to eight participants*. We recommend keeping the number of participants rather low in order to allow a

maximum of time for interactions and the development of positions. A facilitator should guide the participants through the process and should ideally not give an introduction to the issue at stake in order to avoid presenting him/herself as defining the content of what is to be discussed. If necessary, a short video clip that lays out the topic and its dimensions could be shown.

Each participant has a personal board that materializes the four different stages with boxes on which the chosen cards in each stage should be put (see Fig. 1). Next to the board, four piles of cards are placed flipside up. The participants are asked to pick up one pile at the beginning of each stage, to go through the cards and decide on a predetermined number of cards by applying their own rationale for choice (e.g., dislike or agree with a statement, be astonished, find it puzzling, and so on). When every participant has placed the chosen cards on the board in front of him/her (this may take 5–10 minutes, depending on the respective number of cards), the moderator can start to inquire about their choices.

4 Creating the Cards and Deciding on Stages

In this section we address some questions that arise for researchers who would like to adapt IMAGINE to a specific topic: What should I consider when creating the cards, deciding on the exact number of stages, and the thematic focus of these stages?

4.1 Exploring and Analyzing the Issue

In order to come to these decisions, a detailed analysis of the topic to be debated is a necessary prerequisite. This is a crucial element and essential first step in the IMAGINE methodology. In contrast to focus groups, where usually just a discussion guide consisting of themes and questions is developed, more detailed prior research is needed to develop the comprehensive and quite work intensive card material. This research may also include the use of other qualitative research methods such as interviews, media, and document analysis; ethnographic methods; and participant observation or online research. It is not sufficient to roughly survey the topic, but it is necessary to identify the spectrum of concrete arguments, explanations, actors, regulations, images, and examples that together constitute the topic.

In what follows, we will present how we concretely developed the IMAGINE card types and their contents. In the specific case of our research project, the aim of the preceding analysis was to explore the existing technoscientific, political, and cultural discourse and meaning production on nanotechnology. ('Making Futures Present. On the Co-Production of Nano and Society in the Austrian Context', funded by the Austrian Science Fund, project number P20819, PI: Ulrike Felt, see <http://sts.univie.ac.at/en/research/completed-projects/making-futures-present-nano-and-society/>). Since the research we wanted to undertake with IMAGINE was to investigate the public perceptions on nanotechnology in the Austrian context, our analysis had a specific focus on the Austrian context – but we also drew on international resources to give a

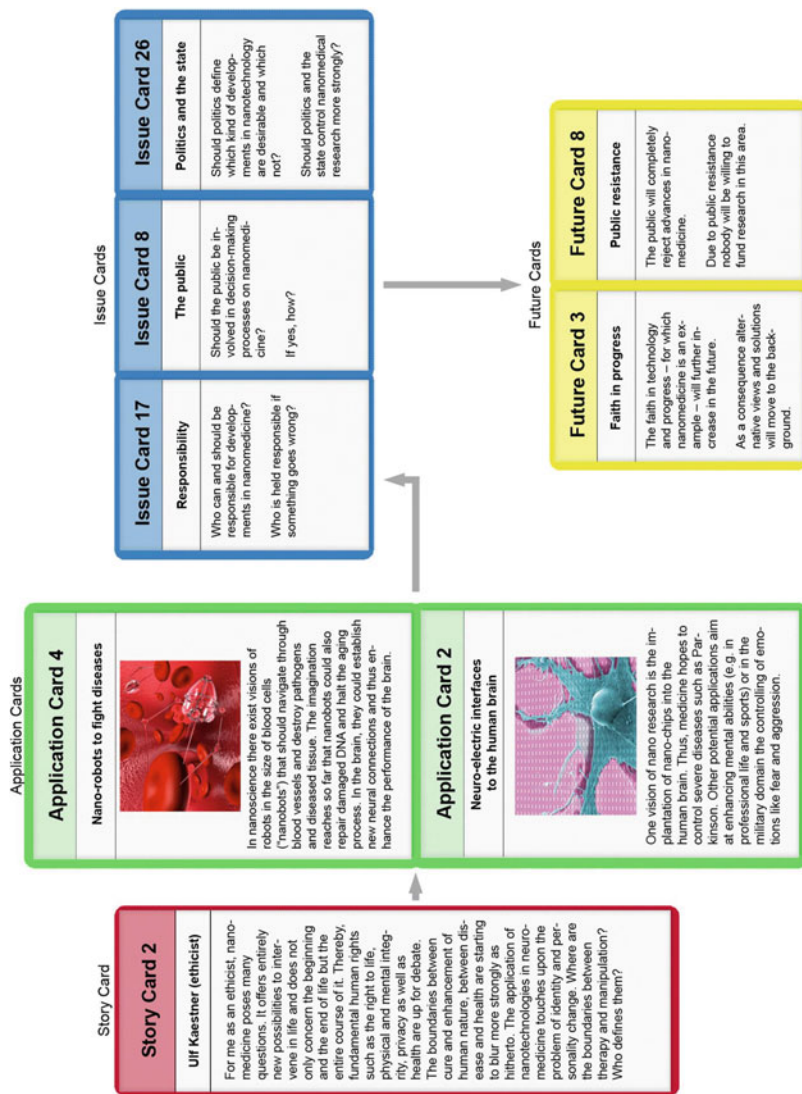


Fig. 1 Schematic representation of a board with a selection of cards. The topic discussed here was nanomedicine (Felt et al. 2014)

broader picture. Our main methods were literature (especially on social and ethical issues) and media research, analysis of policy documents, and qualitative interviews, which we conducted with Austrian stakeholders (among them primarily scientists, policymakers, and representatives from nongovernmental organizations). Such interviews are essential to interpret some of the material found and to add further perspectives. But, we also looked into other projects on nanotechnology and their methodological tools for enabling participation, such as the *concept boards* from the DEEPEN (Deepening Ethical Engagement and Participation in Emerging Nanotechnologies) project (https://www.dur.ac.uk/geography/research/research_projects/?mode=project&id=241, accessed 25 June 2016.) and a PlayDecide card set on nanotechnology.

4.2 Card Types and Choreography

In order to structure the discussion process, we decided to develop four different card types. Each of it addressed a specific angle of the issue to be explored, and their subsequent introduction allowed to gradually build a discussion through different stages. Below, we present the card types in the chronological order of their appearance in the discussion. We generalize their aim beyond the concrete case of the original IMAGINE cards. For specific examples of the cards we used in the project on nanotechnology see Fig. 1 (see also Felt et al. 2015).

4.2.1 Story/Statement Cards

These cards are the first that participants are asked to read and choose from. They contain short statements or narratives as expressed by different actors and are meant to stand for the spectrum of existing positions towards the issue. Calling them “story cards” points to the fact that they are not an enumeration of facts but are meant to show the multiple ways how people create meaning and coherence of a complex phenomenon by developing a position. These cards look like short newspaper columns in which people convey their view on a specific topic in a concise manner. The material for these cards primarily stemmed from qualitative interviews, quotes of relevant actors in media articles, and policy documents. However, the text has not been taken word for word from these sources. In most cases, it was necessary to rephrase and condense statements to get them into an easily graspable format. Moreover, we decided to present all these statements in an anonymous way – that is, we made the actor status visible (e.g., politician, scientist, legislator, doctor, affected person) but did change the name.

4.2.2 Application/Situation Cards

The second stage of the debate is introduced by cards presenting a set of specific applications or situations in which the issue at stake materializes. In the case of nanotechnology, we presented applications already existing for purchase and visions of applications from researchers or nano-visionaries. In other contexts, for example medical ones, these cards could for instance represent key-moments in a healthcare

situation, when choices have to be made by doctors and patients. More recently, in discussion groups on responsibility in research, a range of concrete research situations were presented using three sets of cards through which a debate on these issues in research practice was made possible (Felt et al. 2017; for this version of a card-based discussion method developed to discuss with scientists see also <http://rri.univie.ac.at/aktivitaeten/series-of-group-discussions/> (accessed 10 October 2016). The sources used for the creation of these cards should also derive from prior analysis of the topic, public debates, policy documents, webpages, and many more. This type of cards is meant to render participants' positioning work more concrete and detailed. It should allow to elicit a nuanced view on the situatedness and multiplicity of assessments, i.e., participants might come to rather divergent assessments of the issue when they are confronted with different application contexts or situations. In the project on nanotechnology, these cards included each an illustrative image and a short description of the application. The cards had a promissory tone but also included potential risks and negative implications. In the case of responsibility in research situations, cartoons were used to express the diverse situations in which responsible choice can come to matter.

4.2.3 Issue/Context Cards

After having already discussed societal attitudes towards the topic as well as more concrete applications/situations, the third card type, the issue or context cards, takes the debate to a level at which broader themes and contextual aspects are addressed. Therefore, in the nano case, these cards would address in one or two short sentences/questions a variety of ethical, social, political, environmental, health, economic, and legal issues. These issues were primarily extracted from literature research and were the outcome of our analysis of the collected material. In contrast to the previous card types, much more analytical work was going into their development.

The issue/context cards should include as much potentially relevant issues with the aim to foster a deeper discussion in the IMAGINE groups. The cards mostly included a more abstract question or raised a specific argument. Issues covered in our research were, for instance, questions with regard to the role of the state in governing emerging technologies, who should take responsibility if developments go wrong, or to what degree citizens should be involved in decision-making. This allowed the participants to either try to develop a position to a raised question, to pose it to the group or to agree with or critique specific statements. Generally, phrasing the issues as questions seems to bear the most potential for the discussion. Our experience was that many of these issues already appeared in a more latent form in the first two stages, but that this stage was relevant to make them more explicit and to also raise awareness for issues that were not so evident at first. In this stage particularly, shared concerns were often evident by participants' similar card choice.

4.2.4 Future Cards

These cards mark the final stage of discussion and should stimulate the collective imagination of how the issue at stake would continue to develop, what actor constellations might matter, and what this would mean in terms of present choices.

While past and future developments have been discussed more or less explicitly in the previous stages, this stage focuses explicitly on how the discussants imagine and assess the possibility of potential developments. Whereas the story/statement and application/situation cards are more descriptive, and the issue/context cards are more analytical, this last set of cards invites participants to make more general projective statements. This comprises questions such as where developments could lead, how the future may be shaped by various actors and forces, what this might mean for the individual and society, and how one could intervene in this making of a potential future. Strong utopian/dystopian or highly speculative scenarios, which lacked any rooting in present developments, have not been included.

Additionally, we also included blank cards, on which the participants could write their own issues/situations and futures, for the last two card types.

4.3 Validating the Card Sets and Making Choices in the Choreography

A more practical but nevertheless essential task in creating the cards is to fill them with content that is not only comprehensible for participants coming from diverse backgrounds but also adequately represents the multiplicity of narratives, situations/applications, issues, as well as possible future developments. At the same time, the number of cards should be limited as participants have to read them all before making a choice. In the nano-project we used 6–8 story cards, about 7–9 application cards, 25–30 issue cards and 15–20 future cards. We created much more cards at first and then went through a selection and validation process. First, all members of the research team as well as noninvolved colleagues should read the cards and give their feedback. Second, professionals or experts in the researched field can be consulted to check statements and if the field and its scope has been represented in a balanced and comprehensive way. The feedback process can be carried out in diverse ways, ranging from mere textual editing to more elaborate ranking exercises. Cards can be ranked with regard to different attributes like relevance, readability, value of information, and so on with the aim to condense the card set by sorting out those at the end of the scale. In a next step, the cards should be tested with a user group to ensure that they are understandable and without unwanted ambiguities. Generally, at the end of an IMAGINE discussion it is also recommended to allow a feedback round on the method and card content. Since the actual participants have experienced how the cards work for them, their feedback can help to re-work and refine the cards.

The content of the IMAGINE cards and how they should be written is also affected by group-related design choices. Designers of IMAGINE need, from the beginning, a vision of the participants they want to engage. A decision for homogeneous or heterogeneous groups, for example, often derives from and is aligned to a specific research question and methodology but has also major implications for the creation of the cards. Social groups such as adolescents, elderly people, people with lower formal education, or participants with diverse cultural

backgrounds will demand careful reflection of both cards and contents. In general, this means considering the following points, which all follow the principle of “low entry level participation”:

- *Texts* should be easily understandable; if technical terms are to be used at all, they should always be accompanied with an explanation.
- *Sentences* should be short and straight forward.
- *A larger font* should be preferred to make the reading quick and easy for everybody.
- The *number of cards* should be adapted to the group composition.

The choice of groups also impacts the duration of the discussion and the overall choreography. If IMAGINE discussions are conducted in institutions such as schools, the method might have to be adapted to institutional timeframes. In general, if there exists a shorter timeframe for discussion, the types and number of cards should be reduced. Moreover, specific groups might have a different attention span than others, which then impacts the duration of the discussion.

Another issue that influences the choreography or course of discussion is the question of the aim of the whole exercise. There are two ways to approach this: one that is usually practiced in qualitative research and another that is typical for public engagement. A lot of public engagement initiatives seek for a group decision or shared statement at the end of a discussion process, which most of the time means that some kind of consensus has to be reached. Qualitative research, on the other hand, is more interested in the process as such and the themes that are discussed. Here, leaving things open, even if positions remain incompatible at the end, is not problematic. The former also implies that time has to be planned for an extensive final round, in which people are enabled to formulate collectively a recommendation paper, whereas IMAGINE groups in qualitative research contexts may just end with a short round of reflection among participants.

5 Conducting IMAGINE Discussion Groups

In this section, we reflect on three practical issues with regard to conducting IMAGINE discussion groups: place, moderation, and documentation. First, it is necessary to keep in mind how the place where discussion groups are held, shapes the way the debate may unfold. No setting is “neutral” and thus it is important to reflect on what a specific place or setting might enable or close down in terms of what and how opinions can be expressed. While this is relevant for every research method, IMAGINE calls for a more specific consideration due to its materiality; the fact that it includes a board and several piles of cards that need to be placed in front of every discussant and needs face-to-face interaction between participants. Hence, IMAGINE requires in general a setting in form of a round table.

The choreography and cards act as strong structuring and facilitating tools. This is why there is in principle less need for moderator involvement than in focus groups.

Nevertheless, a moderator is important for the smooth conduct of an IMAGINE discussion group. The main role of the moderator is to know and explain the stages and guide the group through each of them, which includes time management tasks such as keeping an eye on the duration of individual reading and decision-making phases in each stage. While the mode of moderation is always open for choice, the following three elements are important for a good functioning of such an approach:

5.1 Assignment of Turn-Taking

In the first phase of each stage, the participants are asked to choose cards and then present and explain their card choices. Here, the moderator should make sure that all participants get their turn and encourage quieter participants to contribute. Ideally, the assignment of turn-taking becomes a self-directed process among the participants without much intervention by the moderator, especially in the more discussion-oriented periods.

5.2 Keep the Discussion Going

Although the explanation of card choices is one central aspect of the choreography, the main interest of IMAGINE lies in the discussion among the participants that follows. The benefit of alternating more individual and collective phases, however, also poses the risk that the discussion process does not get started. If this is the case, the moderator is required to come up with open-ended questions and comments that stimulate the interaction in the group. It has proven helpful to ask about the participants' opinion about specific cards. For instance, the moderator may suggest the discussion about cards that have been chosen by several participants or inquire why specific cards were not chosen at all. Part of the moderator's task is also to allow room for flexible timekeeping whenever it is in the research interest to keep the discussion going.

5.3 Encourage Discussion Among Participants: Not with Moderator

The moderator should encourage participants to discuss the topic with each other and not enter in a dialogue with individual participants. A general guideline to achieve this is to address the group and not individual people. Moreover, the moderator should not present himself/herself as an expert, because this would prompt participants to ask the moderator questions instead of debating with each other.

Depending on the research question and analytical approach, one may opt for different means to document the discussion process. In general, we recommend to audiotape the discussions and transcribe them (or relevant passages) in a way that includes some details on turn-taking, overlapping speech, pauses, and annotation of

nonverbal activity. Such a transcription system allows making the most of the discussion data without going into too much detail. An alternative or complementary option is to make a video recording. The advantage of visual documentation is that it allows analyzing body language, particularly if there is an interest in how the card choice process unfolds. However, the presence of a video recorder might also affect the discussion in a different way than an audio recorder. Another “cost” is that the analysis of videotapes generally represents a more complex analytical undertaking than an analysis of discourse. A compromise is to complement the audiotape with ethnographic observations, which are also able to capture body language and the appropriation of the card materiality (for such an analysis see Felt et al. 2014, p. 241ff.).

6 Analyzing IMAGINE

In terms of analysis, we suggest a close examination of interactive processes and their role in the construction of meaning. This approach relies on the premise that knowledge, experience, and memory cannot be regarded as fixed entities existing independently in peoples’ minds but are situated enactments emerging within specific circumstances and contexts. It follows that the analysis needs to move from a focus on what is said – the positions and understandings people articulate – to how content emerges through interaction. Here, discourse analytic methodologies can help to explore dynamic meaning-making processes as well as the more tacit moral and social assumptions of utterances (for examples from the analysis of IMAGINE discussion groups see Felt et al. 2015; Schwarz-Plaschg 2016).

In contrast to public engagement, where the focus tends to lie on fast output (e.g., a recommendation paper written by the participants or a consensus on a controversial issue), a discourse analytical approach requires time and social scientific qualifications to produce results. However, IMAGINE can also be carried out as part of a more inclusive and participatory research process that invites participants to co-create the cards and/or involves them in the analysis. We utilized IMAGINE in this way in a participatory school project (“Nanomaterials: Possibilities and risks of a new dimension,” 2010–2012, funded by the Austrian Federal Ministry of Science, Research and Economy under the program “Sparkling Science”) that sought to engage students around the age of 17 in reflecting on the risks and benefits of nanotechnology. In four workshops, we first developed an IMAGINE card set on nanotechnology together with the students, which was then used for the discussion with other groups of students. Then, we jointly analyzed the discussion groups and the students presented the findings at a “Young Researcher Symposium” to other students and stakeholder representatives. One aim of the project was to familiarize the students with the way qualitative research is conducted. Beyond this learning and empowering potential, such participatory research can also ensure the validity of findings and provide rich new analytic material.

As mentioned above, IMAGINE allows to integrate the materiality of and interaction with the cards into the analysis when video recordings or ethnographic

observations are made. Here, our analysis has already shown that the cards stimulate specific practices and serve a variety of purposes for the participants (Felt et al. 2014, p. 241ff). One option is to analyze how the individual participants order and choose cards in the “silent” card choice phase – and to relate these practices to the discursive explanations they give afterwards. Another perspective would be to trace how the cards are used as mnemonic tools to remember the course of the discussion and the positions of other participants. We furthermore found that the frequency in which cards are chosen might display tendencies of those issues that are of central concern, which would need further qualitative exploration.

7 Conclusion and Future Directions

In this chapter, we introduced the card-based discussion method IMAGINE, which we developed as a response to three major challenges in participatory research settings: (1) Rendering issues that are not publicly debated accessible to a wide range of participants; (2) enabling participatory justice, i.e., to partly compensate for differences among the participants in discussion groups that may affect their ability to participate; (3) countering the classic lay-expert divide by bringing expertise without experts to the table.

The preparation of sets of cards allows to present and structure an unfamiliar or complex topic and to discuss it from a variety of perspectives. The potential of IMAGINE lies in the flexible card material and the way in which specific card types are utilized in the various stages of discussion. This means that it manages to structure debate, while leaving it open at the same time. As the cards bring a diverse spectrum of opinions, possibilities, and problems into the discussion, it has proven easier for participants to embrace a position which is marginalized, stigmatized, or a taboo in the wider public debate via a card. The variation of angles from which to address a matter of concern further adds a developmental perspective to the discussion as people can gradually construct and work on their assessments, revise positions, or reinforce them.

This approach, therefore, also seems fruitful when an issue is already strongly polarized in the public space. In this case, the cards, as material-semiotic resources, could be used to deconstruct fixed positions into smaller entities and, allow to open up the possibility of reconfiguration. The cards, thus, render visible the complexity of any scientific and technological issue in society, point at the large network of actors involved, and thus, make an issue more broadly assessable for the discussants.

The method is particularly apt for understanding how people order a specific topic, which becomes visible through the card selection processes. It allows to better understand the frames of references people work with but also what they need for developing, defending, or adapting a position towards an issue. This becomes palpable through the individual arguments justifying their choice of cards but also through the follow-up interaction. The method further invites to explicitly relate past experiences with future expectations. This is done as the final phase of a longer argumentative process is less open for speculation but constitutes more an

argumentative projection exercise. Yet, it also enables the moderator as well as later the analyst to observe the nonchosen cards/issues and thus to address and reflect on absent presences (Law 2004).

Overall, the method is particularly apt for projects in which the core interest is to get a better understanding of how participants articulate their positions, where zones of conflict arise and where agreements are emerging, and what things can be said in such a semi-public setting and which are more contested. It is less fitting if the expectation is to have one opinion at the end of the process.

Most importantly, IMAGINE is *not a ready-made tool*. It is an open, process-oriented method that needs careful adaptation to the situation or issue to be discussed. This means considering the multiplicity of ways in which to assess any matter of concern, the diversity of participants, and the specific cultural context in which it is performed, to mention a few obvious factors. The card-based method, therefore, demands considerable input from the social scientists who want to use IMAGINE in their qualitative research and/or engagement exercise, as they have to perform a careful qualitative analysis of diverse sets of available background materials as well as produce case-specific data such as interviews. IMAGINE, thus, has to be seen as an integral part of a broader process of understanding an issue and of triggering engagement with it, rather than an isolated method.

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Timeline Drawing Methods

67

E. Anne Marshall

Contents

1	Introduction	1184
2	Definitions and Formats	1185
3	Advantages of Using Timelining Methods	1187
3.1	Richer and More Complete Data	1187
3.2	Establishing Rapport	1188
3.3	Participant Engagement	1188
3.4	Flexibility	1188
3.5	Language	1189
3.6	Power Differences	1189
3.7	Professional Settings	1189
4	Challenges of Using Timelines	1189
4.1	Personal Content	1190
4.2	Confidentiality	1190
4.3	Assumptions of Linearity	1190
4.4	Analysis	1190
4.5	Reporting	1191
5	Review of Timeline Research	1191
6	Four-Phase Model for Using Timelines	1197
7	Conclusion and Future Directions	1198
	References	1198

Abstract

Qualitative researchers are continually seeking approaches that will yield in-depth and high-quality interview data. Incorporating a timelining method adds a visual representation related to the experience that can anchor the interview and helps focus the participant on key elements. Timelining can provide participants

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with a way to engage their stories deeply and even help to create new meanings and understandings. Timelining is particularly appropriate with sensitive and complex topics or when interviewees' oral language expression is limited due to a variety of circumstances. This chapter begins with definitions and descriptions of timeline methods used in qualitative inquiry. Potential advantages and limitations are discussed and several specific applications illustrate how different methods have been utilized. A five-phase model of the timelining process is proposed: Introduction, Methodological Decisions, Application, Immediate Reflection, and Analysis/Reporting. Finally, future directions and ideas related to timelining methods in qualitative research are suggested.

Keywords

Complementary research methods · Creative research methods · Qualitative research methods · Timeline drawings · Timelines · Timelining methods

1 Introduction

Interviews are the main means of data collection in qualitative research. Whether structured, semistructured, or open format, interview data form the basis. However, several authors have called for more varied and creative approaches to qualitative inquiry in order to better reflect the rich and multidimensional aspects of participants' experiences (Deacon 2000; Ponterrotto 2006; Adriansen 2012; Kolar et al. 2015). Increasingly, researchers are utilizing visual data collection methods such as timelines, life grids, mapping, drawing, poetry, video, photographs, graphs, and writing (Marshall and Guenette 2008; Blanchet-Cohen et al. 2003; Groenwald and Bhana 2015). Most often, researchers use visual methods in a complementary fashion, together with some form of interviewing. Researchers who have used visual methods have identified a number of advantages, including greater data depth and detail, enhanced rapport with participants, and the ability to conduct interviews with those whose expressive language is limited. See also chapters in Section 2 in this volume.

Timelining methods show particular promise for qualitative researchers and are the focus of this chapter. Timelines are visual representations of particular and selected events or "times" in a person's life. Depending on the focus of the research, timelines can span a participant's lifetime, a certain number of years, or even a few months. Timelines can be constructed by a single person (participant or researcher) or collaboratively and at different times in the research process. Analysis can be part of the interview or done later, and done in different ways. Timeline methods can be adapted to suit a broad diversity of research questions, interview formats, participant groups, and settings (see ► Chaps. 68, "Semistructured Life History Calendar Method," and ► 69, "Calendar and Time Diary Methods" in this volume).

Despite their utility, flexibility, and ease of application, there is surprisingly little in the scholarly literature about how to use timelining methods (Berends 2011).

In this chapter, I begin with definitions and descriptions of timeline methods used in qualitative inquiry. Potential advantages and limitations are discussed next. Several specific applications of timelining are described in order to illustrate how different methods have been utilized. Based on a review of these and other studies in the literature, a four-phase model of the timelining process is proposed: Introduction and Methodological Decisions, Timelining Application, Immediate Reflection, and Analysis/Reporting. The chapter concludes with some suggestions for future directions related to timelining methods in qualitative research.

2 Definitions and Formats

Although researchers in diverse disciplines have used timelines for many years, there appears to be no universally accepted definition (Berends 2011; Kolar et al. 2015). Scholars and researchers who have employed timeline methods tend to define them in terms of their particular use. Adriansen (2012) describes timelines as collaboratively constructed visual representations of the main events of a person's life. Berends (2011, p. 2) defines a timeline as "visual depiction of a life history, where events are displayed in chronological order." A timeline can be as simple as a straight line with points or dates marked on it or it can be an elaborate depiction using colors and images. Timelines can also include text such as a description of the event, an explanation of the meaning of the event, or even feelings and thoughts associated with the event. With respect to format, timelines can be products and images that have already been prepared (by the researcher or others) as well as products created by participants in the interview, or what Jackson (2012, p.415) terms "respondent generated imagery." The possibilities are virtually endless, depending on researcher stance, research purpose, time available, resources, participant interest, and potential audience.

The most widely used timelining method is the classic *straight line*, with key events marked along it (see Fig. 1). This approach is easily understood and can be accomplished in as little as 10 or 15 min, yet can yield a surprising amount of data for exploration and reflection. Moreover, participants can construct this type of timeline on their own before or after an interview.

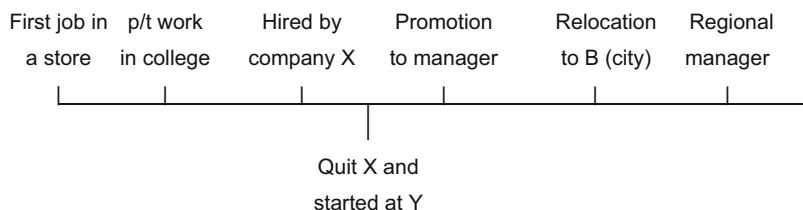


Fig. 1 Example of a simple timeline



Fig. 2 Meandering timeline

A variation of the horizontal timeline is a *meandering line* that includes “peaks” and “valleys” or changes in direction to indicate “choice points”, pivotal experiences, or events of particular significance. Text is often added and different colors may be used. Figure 2 illustrates an example of this type of meandering timeline, showing a participant’s experiences related to history of surviving abuse. The colors had particular meanings that were described in detail during the interview.

Life grids are a form of timeline that are still linear but have two dimensions. Life grids have been used frequently in life course research (Nelson 2010; see also ► Chap. 68, “Semistructured Life History Calendar Method” in this volume). In her study of Indigenous helpers, Stewart (2007) used a life grid variation she called a *story map* to complement her in-depth interviews. The story maps had time on the vertical axis and literature-derived data themes on the horizontal axis. A summarized example is shown in Fig. 3.

There are also nonlinear or *drawing* type timelining methods. Jackson (2012, p. 415) describes this type of *participatory diagramming* as “drawings, sketches or outlines demonstrating or explaining a social phenomenon.” Saarelainen (2015) created a life tree drawing process (described below) that was particularly suited to an exploration of life stories among young adults during cancer remission

	Participant's world				
	Self	Indigenous culture	Community	Mental health & healing	Counseling practice
Past experiences	Background self-identity roles	Roots Personal history Events	Setting the context Past connections	Incidents Sites	Past work experiences
Present experiences	Current status Level of awareness	Current support	Current connections	Community experiences	Current work experiences
Future intentions	Outcomes Personal development Self-identity	Future support	Future connections	Plans for future schooling	Future work expectations

Fig. 3 Story map template for data analysis

3 Advantages of Using Timelining Methods

Researchers who use timelining have identified a number of benefits associated with their use. These include richer and more complete data, enhanced rapport, greater participant engagement, a more collaborative interview process, appropriateness for sensitive topics, and mitigation of language limitations. Several of these factors are related; for example, better quality data is more likely when participants feel at ease and are actively engaged in the interview process.

3.1 Richer and More Complete Data

Qualitative research has been criticized for being too verbally focused; thus, including a visual element such as a timeline can make findings more accurate and complete (Berends 2011; Jackson 2012). Having more than one source of data assists in obtaining a more complete sense of participants' experiences. Multiple data sources (writing, drawing, and speaking) represent different aspects of the same stories that can be analyzed side by side, thereby creating triangulation for interpretive confirmation (Saarelainen 2015). Berends (2011) suggests that including a timeline procedure may uncover novel or expected aspects of the phenomenon being studied and prompt researchers to reconsider theme categories, while also

providing a method of triangulating across data sources. Researchers who use timelines consistently attest to the richer and more in-depth data that result (Nelson 2010; Sheridan et al. 2011; Adriansen 2012; Groenwald and Bhana 2015). Laying the story out visually can draw attention to patterns in the narrative, as well as to contradictions and inconsistencies (Patterson et al. 2012). This can then lead to further explication and participant reflection on meaningful events and impacts. Moreover, shifting the focus in an interview to something novel or different can stimulate a new participant perspective or enhanced description of experiences (Guenette and Marshall 2009; Kolar et al. 2015).

3.2 Establishing Rapport

Many researchers report enhanced rapport with participants when using timelines (Jackson 2012; Kolar et al. 2015). Qualitative interviews often involve a chronological orientation or story-like aspects. Participants are familiar with describing events over time and usually feel comfortable with having a visual depiction of events included as part of the research process (Patterson et al. 2012). Rapport is particularly enhanced when the participant creates the timeline or works together with the researcher on it (Kolar et al. 2015). Timelines and other engaging “side-by-side” methods have been found to be particularly helpful with marginalized participant populations where there may be some mistrust or hesitancy (Jackson 2012) and with sensitive topics (Nelson 2010; Berends 2011; Saarelainen 2015; Rimkeviciene et al. 2016).

3.3 Participant Engagement

Related to rapport, timelining methods have been observed to stimulate a greater level of participant engagement that yields richer and more complete data (Guenette and Marshall 2009; Berends 2011). Co-constructive and collaborative narrative type designs are engaging because the participant and researcher interact as the timeline and the interview unfold (Marshall 2009; Patterson et al. 2012). Creative drawing methods such as Saarelainen’s (2015) *life tree drawings* are particularly engaging because participants bring their own preferences and meanings to the timelining process.

3.4 Flexibility

Timelining methods are flexible and can be adapted to a multitude of diverse participants, purposes, settings, and research designs (Nelson 2010; Berends 2011). They are particularly useful for hard-to-reach and marginalized populations that often have been excluded from research (Jackson 2012). Timelines have been successfully applied in focus groups, child and youth populations, and cross-cultural settings. They are also amenable to structured and unstructured data analysis approaches (Marshall 2009).

3.5 Language

With visual data collection methods, there is less emphasis on verbal language skills, which is of benefit when working with younger participants or with those whose language or cultural backgrounds are different to those of the researchers (Jackson 2012; Nelson 2010). Even if participants are verbally skilled, nonverbal techniques can capture emotions and experiences in greater depth and detail than verbal descriptions alone. Visual methods such as timelining can be particularly helpful when qualitative interviews are not complete or fully coherent due to factors such as language difficulties, traumatic experiences, anxiety, or impaired memory (Patterson et al. 2012; Rimkeviciene et al. 2016). With timelines or drawings, “stories can be evaluated as a whole, even if a coherent meaning . . . has not presented itself” (Saarelainen 2015, p.73).

3.6 Power Differences

Using nonverbal data collection techniques such as timelines can help minimize the expert role of the interviewer and decrease perceived power differences between interviewer and interviewee (Patterson et al. 2012). Visual methods often involve a high degree of participant input and thus can facilitate a more collaborative or coconstructed experience. Adriansen (2012, p. 49) maintains that timeline interviews bring interviewees “closer in the landscape of power”; participants have more power because there are no set interview questions and they are able to select important events themselves.

3.7 Professional Settings

In educational settings, timelines have been used for personal and career-related exploration with individuals and groups of students (Guenette and Marshall 2009; Marshall 2009). For clinical investigators such as nurses, counselors, or psychologists who are affiliated with treatment settings and training programs, timelines can complement in-depth interviews with patients and clients. They can also be used in clinical supervisions and to assess program effectiveness. In alcohol treatment, Bryant-Jeffries (2001) observed that the use of timelines (or lifelines) could help bring client realities into the therapeutic setting and highlight the significance of events.

4 Challenges of Using Timelines

Some of the advantages of timelines also pose challenges – the very depth and detail valued by researchers can pose a threat to anonymity, for example. Other challenges include the very personal nature of timelining, the implication of linearity, data analysis, and reporting or publishing decisions.

4.1 Personal Content

Adriansen (2012) cautions that ethical issues can arise due to the personal nature of timelining. Participants may be sharing experiences and information that they have not divulged previously or be describing sensitive issues. Researchers have to be alert and willing to stop or divert the interview if the participant appears to be distressed. Timelining is not always successful with or appropriate for everyone – not all participants are comfortable with sharing personal information or actively collaborating with the researcher in the interview process. It is important that the timelining process and the potential impacts be clearly described in recruitment materials and during the informed consent phase and that potential participants are able to ask questions about the procedures.

4.2 Confidentiality

Timelines contain specific and sometimes detailed information about people and events. While this is desirable for researcher understanding, it does raise issues about confidentiality. For reporting and publication purposes, the names of people and locations can be disguised or changed to a more descriptive term; for example, “relative” or “boss” could be used in place of a person’s name and “city” or “workplace” instead of location or company names. Even with these precautions, however, a participant might be identifiable, depending on the events depicted and the amount of detail. Adriansen (2012) contends that participants’ timelines should not be published in papers; the information from them should be integrated into the data analysis. She also suggests that timelines are not appropriate for interviewing insiders.

4.3 Assumptions of Linearity

The visual timeline may appear to oversimplify or assume a linear sequence to participant experiences (Berends 2011). This can be particularly problematic if the timeline is completed before an interview or by the participant on his or her own – the tendency is to follow instructions (that are also linear step-by-step) and proceed in a chronological fashion that may emphasize time accuracy more than experiences or the significance of events. Overemphasis on linearity is easier to avoid when the researcher is present and able to probe for meaning or when the timelining procedure is embedded in the interview.

4.4 Analysis

Although there has not been much written in the literature about how to do timelines, there is even less written about how to analyze them. Kolar et al. (2015) point out

that timelines can complicate data analysis because they are more visual than verbal; it can be difficult to convey the meaning or significance of timeline events in text. The type of analysis needed partially determines the way the interview is conducted. Berends (2011) cautions against over-reliance on timelines because the process can simplify a life into a linear sequence of events that can cause loss of depth; she recommends combining timelines with interviews.

4.5 Reporting

Challenges in reporting and publication are often related to confidentiality concerns. Program evaluation reports, professional practice investigations, and scholarly journals all have particular audiences whose members may be familiar with the program, treatment intervention, or research site in which timelines were gathered. The depiction of timeline examples or the description of specific events may provide enough information for participants to be identified. On the other hand, anonymizing these types of data can rob them of their meaning and obscure thematic relationships. Berends (2011) suggests that depicting a composite representative timeline instead of individual timelines has the advantage of highlighting typical underlying factors and relationships between events without threatening confidentiality.

The specific studies described in the next section provide examples of how researchers and scholars have used timelining procedures in particular qualitative research contexts.

5 Review of Timeline Research

Adriansen (2012) writes about using timeline interviews as part of life history research. She maintains that life story research helps to more fully understand a person's perspective of their own life story as well as the patterns of their story in context. In her doctoral research in Africa, Adriansen found that that using timelines yielded the most interesting and in-depth life story data. However, she was surprised to discover that little had been written about this method of data collection, particularly how to actually do it.

In her paper, Adriansen describes conducting timeline interviews with research participants that typically take about 2 h. She provides a detailed description of the steps she uses in the timeline process. In her approach, the researcher often does the timelining in response to the participant's story; however, interviewees can participate in the drawing and/or the event writing. Usually, a timeline is drawn in the center of a large piece of paper and important events are marked on it with different-colored pens. Different lines can represent different perspectives. For example, there can be a line in the middle depicting the core or main story, with other lines branching off or drawn separately near the edges of the paper. Sometimes the paper is divided into two or more sections, representing different contexts such as

family, work, neighborhood or local, national, political arenas. The researcher or interviewee can also add contextual information and explanations. As the interview unfolds, the timeline can change. Adriansen claims that using a timeline actually makes a story less linear because having the visual anchor allows the participant to jump around to different time points and construct multiple stories without losing key elements.

Kolar et al. (2015) maintain that little research has been done on using visual methods and that much that is available focuses on content rather than on form. Few studies include supporting examples or discussion of how the participatory space is created. Kolar and colleagues describe two of their studies using timelines to investigate resilience among marginalized groups. One study included male and female street-involved youth aged 18–26 and the other involved young South Asian women; all participants had experienced violence in their lives. The approach to timelining was flexible, depending on participant comfort and preference. Sometimes the timeline was created first, followed by questions referring back to the timeline to elicit contextual information; other interviews were more interactive, involving the simultaneous creation of the timeline along with the interview questions and probes about important events as they are shared. Kolar et al. observed that timelining helped to bring participants' life stories to the forefront and added contextual richness. Moreover, they found that the researchers were able to shift the topic away from sensitive or emotional material if needed and also to emphasize a focus on strengths and resilience. The timelines were coded for both content and form. Kolar et al. distinguish between *List-like timelines* (chronological and text-heavy lines with notes) and *Continuous-line timelines* (horizontal lines that go up and down). The authors suggested that timelining is a particularly useful method when there is only one chance to engage with participants due to confidentiality issues, the transient nature of a population, or financial constraints.

Drawing primarily from a study involving 112 mostly male participants in their 20s and 30s who were substance users, Berends (2011) describes the benefits and challenges of using timelines together with in-depth interviews. She maintains that timelines are useful for aiding memory, making comparisons to other data sources, allowing participants to construct their own reality, identifying common themes across participants, and situating a phenomenon in context. Focusing on exploring pathways to alcohol treatment, Berends used a timeline tool, a sheet of paper with a horizontal axis where drug use was plotted above the line and treatment experiences below the line. Timeline data were compared to interview data for consistency and recurrent themes (such as age when drug use started, types of drugs used, and treatment settings) were identified. With regard to analysis and interpretation, Berends points out that timelines and interviews are not necessarily records of fact but a way of constructing meaning to bridge memory with reality. To preserve participant anonymity, she constructed composite timelines that reflected more than one participant's experience. In that process, the voice of individual participants is then lost; however, it can be reintroduced by using carefully chosen illustrative quotes in the report or publication. Berends recommends, "generalities drawn about participant experiences should be reflected in individual journeys" (p. 8); thus,

common themes across participants should be complemented by quotes and examples from individuals in reports and papers for publication.

Jackson's 2012 study focused on identity development with multiracial participants in a clinical social work context. Jackson contends that the aim of timelineing in clinical practice is to help client reinterpret the past and their self-perceptions in context, while remaining sensitive to cultural factors. In this study, participants spent 20–25 min completing timelines with minimal instructions and only colored markers and blank paper as materials. Then they participated in an audiotaped interview to discuss the experience. The timelines and interviews were analyzed for themes based on what the literature suggested about the research topic. Jackson identified three levels or *sites* related to data collection and analysis. The *production site* of the timeline, or the research context, involved reassuring participants about the process, and giving them control by having them select a key event and starting point. The *image site* was analyzed based on the organization, content, and colors of the timeline. The *audience site* referred to the researcher's position in the research. The researcher created some distance or safety by leaving while timelines were created and by providing minimal instruction; however, the researcher's position as a knowledgeable insider resulted in personal connection to the participants' stories. An insider position, however, poses some challenge for analysis and interpretation. Jackson observed, "as an *insider*, I must be conscious of and reliant on the meaning participants attach to their visual timelines, instead of my own interpretations" (p. 426). Visual methods are empowering and participant-centered; they elicit a more complete illustration of a phenomenon because they are able to evoke participants' emotional experiences that do not always emerge in interviews. There are also some cautions: the linearity of timelineing can be constraining, some participants may be uncomfortable drawing, and the method has not been well described or researched.

In their study with substance using adolescents and their parents, Groenwald and Bhana (2015) used the *lifegrid* timelineing method. These authors describe the *lifegrid* (or LG) as a matrix of rows and columns that represent years and events, respectively. Relevant events are selected for inclusion in the lifegrid based on the interview topic, thus, that the finished product shows how and when the participant's life changed over a particular period of time. The LG process also included a "formative phase" intended to put participants at ease and to identify key areas of focus. Groenwald and Bhana conducted two interviews with each participant; the first involved filling in the lifegrid and the second was a review of the lifegrid, using it to help the participant recall events and chronology in more detail. Parent and children were interviewed concurrently to cross-reference for accuracy. The researchers found that most participants wanted the researcher to fill out the LG, which had the unintended benefits of facilitating the interview flow and minimizing concerns about whether they were doing it correctly. Written chronologically, the LG permits flexibility and allows participants to jump back and forth when talking about their experiences. Researchers make notes of the event dates for coding accuracy.

Groenwald and Bhana claim that the advantages of using lifegrids in qualitative research include participant engagement, support for sharing experiences, and

detailed descriptions of retrospective experiences. Accuracy and reliability of memory is not as important as the meaning participants ascribe to events.

Life story mapping has some similarity to the life grid method. Stewart (2007) explored Indigenous helpers' stories of mental health and healing using story maps (see Fig. 3 above for a summarized map) to complement in-depth narrative interviews. The story maps served to organize participants' recounting of past and present experiences and future intentions as they related to the focus of the inquiry – how professional counselors developed their approaches to Indigenous mental health counseling and healing. Along the horizontal axis were five structural categories chosen a priori, based on literature reviews and the research question: self, Indigenous culture, community, mental health & healing, and counseling practice. On the vertical axis were three time dimensions: past, present, and future, yielding 15 cells in total. Working with transcribed first interviews in which these elements had been explored in depth, Stewart coded the data using the categories and dimensions above, then constructed a map by inserting the specific participant data content codes into the different cells of the map. The map thus created a visual depiction of each participant's specific and particular story as it related to the content categories and time dimensions. In addition, the map resulted in a more penetrating analysis because it allowed the researcher to use a format that revealed patterns within the story. In a second interview, the map and emerging patterns enabled both the participant and the researcher to extend, amend, reconstruct and make sense of the story in a deeper way than simply rereading the story and identifying a list of content themes. All participants observed that the story maps helped them to *see* their story in a more holistic manner over time and facilitated their identification of missing or incomplete elements.

Nelson (2010) adapted the typically quantitative and structured Life History Calendar (LHC) method into a semistructured qualitative interview. The LHC is a printed matrix with temporal cues (days, months, years) presented horizontally and domain cues (categories related to marriage, living arrangements, educational histories, work histories) presented vertically. To counter this limiting structure, Nelson's 2010 adaptation started with a blank page that participants filled in with colored markers and stickers, beginning wherever they liked. This open format helped with rapport, depth of sharing, and identification of context. Participants were Mexican or Mexican-American college students aged 19–22 years who had taken part in an extracurricular program at the beginning of high school. Most were young women from working class families. In a 2-h interview, Nelson explored the impact of their earlier extracurricular activities and how these influenced their educational paths. She observed that giving the participants choices encouraged feelings of ownership and allowed for the delay of emotionally painful stories until rapport was established. See also ► Chap. 68, "[Semistructured Life History Calendar Method](#)" in this volume.

Saarelainen's (2015) creative and nonlinear approach to timelining utilized *life tree drawings* with young women and men aged 18–34 years old who were interviewed during the time of cancer remission. The interviews focused on "how cancer impacts the patient from the perspective of one's life story" (p.68). Using a

method called *visual narrative inquiry*, the participant and researcher coconstructed meaning from the participant's experiences, which were described verbally and also depicted visually with a drawing of a tree. The idea of a tree as a metaphor for life is familiar to many people; the task was thus accessible and easily understood by participants. They were given a blank sheet of paper and a black marker, and then simply asked to think about their life as a tree and to draw what that looked like. Other colored markers were placed on the table. Participants were asked to explain the meaning of the signs and symbols they used and how the components of the tree were related. Saarelainen noted that color was used symbolically: green and pink denoted hope and healing; black represented illness and negative events. There were three life tree types drawn by participants: *neutral trees* used normal tree colors, *multiple-element trees* used colors that symbolized emotional meaning, and *thematic trees* included words that referred to periods of life or specific events. Themes were either written by participants on trees themselves or assigned later by the researcher. Data analyzed included the life tree drawings, interview recordings and transcripts, and blog posts written by the participants. Saarelainen used a critical approach for visual analysis of the drawings, focusing on the image production, the image itself, and the audience. With this particular population of cancer survivors, the life tree drawing was considered to have an advantage over liner-type timelines because it did not have an ending point that could be a reminder of death for participants. For future research, Saarelainen recommended making the life-tree drawing process more co-constructive, allowing participants a more active role and chance to give feedback, and getting participants together for group discussion of their experiences.

In their study of weight loss, Sheridan et al. (2011) created a *timelining over time* method. Their nine participants had once been obese but had lost between 23 and 62 kg (27–44% of weight) and maintained the weight loss for 5 years or more. The study was termed a *graphic elicitation*, defined as a visual method based in drawing or art that create diagrams or drawing for the specific purpose of the research. Participants were interviewed four times over a period of 2–4 weeks; they chose the time frame for the timeline graph, focusing on times when their weight was of particular concern. A graph was constructed, with time depicted horizontally and weight vertically. In this study, the researchers drew the graph, but participants decided what to include and in what order to plot events they had chosen. Describing and drawing the graph provided a preliminary framework that facilitated the sharing of the story. Although the original intention was to do the graph first and then discuss it, researchers found that the two parts melded together and that completion of the graph involved a great deal of storytelling. Participants kept the graph between sessions and were instructed to add to it or change it based on their own reflection or input from significant others. The interviews and timelines were supplemented with objects brought in by participants, such as photos, clothing, journals, and medical documentation; these helped to add details.

The graphing process in Sheridan et al.'s (2011) study was described as largely nonlinear, but a central storyline appeared to hold the different threads of the narrative together. The method provided insight into the different ways participants experienced time (historical, circular, cyclical, spiral, personal, and future). The

authors observed that “time is not simply a ‘series of “nows,” instant that exist along a timeline’ but an abstract (re)presentation of time. . . *doing timelining* plays with and manipulates this linear (pro)portioning of time.” (p.560). Sheridan and colleagues thought that the visual elements in timelining helped participants to focus on the topic and comprehend the scope of the project, as well as elicit layers of experience that might not otherwise have emerged.

Patterson et al. (2012) interviewed 31 male and female participants aged between 26 and 66 years of age about their experiences of homelessness and mental illness. The authors maintain that most homelessness studies emphasize individual factors and daily experience rather than structural inequality and social context. Their study involved narrative interviews and timeline construction. Content analysis of the 1–2-h interviews yielded three main themes: Longstanding Social Devaluation, Feeling Trapped, and Lac of Autonomy. Next, timelines were constructed by the researchers to illustrate the personal stories shared by participants regarding access to social determinants of health and resulting impacts. The timelines were analyzed for timing and order of events as well as context and the researchers constructed an aggregated timeline mapping out key themes and common patterns that provided a generalized view of participants’ experiences. Patterson and her colleagues found that constructing timelines in conjunction with narrative interviews facilitated rich data and allowed them to examine trajectories of events and experiences.

These researchers asserted that the timeline method helped them move toward an insider perspective, helped organize a wealth of data, and revealed aspects that could not be accurately described in words. The limitations noted included some underreporting of stigmatized behaviors, power imbalances, the retrospective creation of timelines without participant involvement, a false implication of linearity, and oversimplification in the aggregated timeline. Despite these limitations, Patterson and colleagues claim that timelines anchor life experiences in the context of developmental periods and can effectively map stories of cumulative adversity and resilience; the research issue or question is placed in the context of a broader life story.

Research by Rimkeviciene et al. (2016) involved participants that could be termed at-risk or marginalized – people who had attempted suicide. Two studies were conducted: the first was with eight male and female participants between the ages of 20 and 50 who had attempted suicide at least twice and the second study involved 49 participants aged 18–35 who were in hospital after recent suicide attempts. The research focus was on understanding suicide as a process and clarifying the role of impulsivity in the decision to attempt. The aim was to obtain rich qualitative description of thoughts, feelings, interpretations, and reactions to significant events contributing to the choice to attempt suicide. Timelines were drawn on blank paper, starting and ending wherever was relevant for the participant. The researchers found that usually the most important events were described first; more detail emerged as the interview proceeded.

Similar to other studies involving sensitive topics, Rimkeviciene and colleagues observed that giving the participants greater control over the interview direction allowed them to shift away from difficult topics when needed. Some participants

struggled to recall accurately and this brought up emotions such as annoyance or fear of disappointing the researcher – it was suggested that the interviewer should normalize these feelings, so participants do not feel pressured to make things up. Final narratives generally capture that participant's *narrative truth*; facts can sometimes be triangulated with other sources. The timelining process captures timing of significant events, thought processes, decision-making, and emotional fluctuations. The participants benefitted by gaining a greater understanding about the interrelatedness of events, actions, and emotions. The authors also note that when talking about sensitive topics in research interviews, it is important to prioritize the participants' well-being while avoiding straying into a therapeutic role. Strategies used to protect participant well-being included ending with a nonemotional task, leaving space for processing the experience, and follow-up support from referring agencies.

6 Four-Phase Model for Using Timelines

Based on a review of the above and other studies in the literature, a four-phase model of the timelining process is proposed: Introduction and Process Elements, Timeline Application, Immediate Reflection, and Analysis/Reporting.

Introduction and Process Elements, similar to what Groenwald and Bhana (2015) call the “formative stage”, is a key phase that sets out expectations for the timelining and interview process as well as the roles for participant and researcher. The process will be new for most participants, so it is particularly important that there be enough time for detailed explanations and time to answer questions. It is usually preferable that participants have as much information as possible in advance so that the informed consent at the beginning of the interview is not inordinately long (Marshall 2009). Rapport begins in the Introduction phase; this is a key element for participant commitment and engagement in the research. Depending on the research design, some *Process Elements* are also part of the Introduction: whether timeline and interview are sequential or occur together, who creates the timeline, how much description or narrative takes place, and (importantly) whether these elements are decided beforehand or whether the process can evolve more organically. Experienced researchers tend to offer more flexibility, guided by participant preferences and judgment about how well the interview is proceeding. In contrast, some research designs and timelining methods work best with a set structure that is clearly laid out and followed.

The *Timelining Application* is the second phase, where the chosen interview and timeline method takes place. Because this process can be long and taking place over two or more sessions, reminders and explanations about what is coming next can be helpful – Munhall (1988) terms this “process consent.” If there are changes in sequencing or format of the process, they should be clearly acknowledged and consented to by the participant. Variations should also be mentioned in reports and publications describing the research.

The *Immediate Reflection* phase is a familiar one for qualitative researchers; field notes and reflection sessions are widely used practices. Timelining is more likely

novel for the participants and may be for the researcher as well; observations, thoughts, and constructive suggestions can assist in improving its effectiveness and lead to further methodological innovations and implementations. Participants' experiences will probably be diverse and may be relevant to data analysis and interpretation. As noted by many researchers, there is very little written about analysis and interpretation of timelining data; systematic reflections on form and content will further refine the process (Patterson et al. 2012; Kolar et al. 2015).

Analysis/Reporting is the final phase, informed by the preceding ones. Decisions regarding the timelining process and any changes that occurred will have an effect on analysis of the data. For example, if the participant created and drew the timeline by him or herself and wrote in explanations, this type of participant-generated data would be analyzed differently than a timeline or life grid that was filled in by the researcher. A timeline completed beforehand and debriefed in an in-depth interview would be analyzed differently than one co-created with a researcher during an interview session. Participant and researcher reflections from Phase 3 would be important information for some of the analysis and interpretation decisions in Phase 4.

The final report or paper/chapter for publication should outline the steps and procedures in the timelining process. In the qualitative research tradition, writing would ideally include *in vivo* observations as well as participant quotes to illustrate data themes and categories in order that the reader can understand the process followed. Representations of an individual or composite timeline are particularly helpful in depicting the process, although considerations of anonymity as described above by Berends (2011) are important to address, perhaps together with participants.

7 Conclusion and Future Directions

As suggested by several authors, more research and more specific descriptions of timeline processes, adaptations, and applications are needed. Graduate students can be encouraged to include visual methods such as timelines in their thesis research. The publication and dissemination of research studies and practical "how-to" tips will contribute to the further development of timelining and other visual methods and contribute to new ones. It is hoped that the application of the four-phase process model will generate more thorough information about timelining methods and stimulate further refinement of the model.

Timelining methods are adaptable to a diverse array of theoretical frameworks, epistemological approaches, and participant contexts. They show great promise for extending and enriching qualitative interviewing.

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Semistructured Life History Calendar Method

68

Ingrid A. Nelson

Contents

1	Introduction	1202
2	Life Course Theory	1203
3	The Life History Calendar	1204
4	The Evolution of the Life History Calendar	1205
5	Adapting the Life History Calendar for Qualitative Studies	1207
6	Implementation	1210
6.1	Time Cues	1210
6.2	Domain Cues	1211
6.3	Starting Point	1211
6.4	Materials	1212
6.5	Data Entry and Analysis	1215
7	Conclusion and Future Directions	1215
	References	1217

Abstract

The Life History Calendar (LHC) methodology was pioneered for large-scale quantitative life course studies but has since been adapted for various research goals across the health-related fields and social science disciplines. This chapter explores the potential of a semistructured Life History Calendar administered in tandem with open-ended interviewing to facilitate qualitative life course research. By merging the depth across multiple social contexts characteristic of the Life History Calendar method with explanatory data gleaned from interviews, this semistructured protocol succeeds at producing nuanced longitudinal data. In this chapter, I highlight the benefits and limitations of the semistructured Life History

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Calendar method, address common implementation issues, and offer examples of how the semistructured Life History Calendar method has been used to study trajectories of education, employment, health, and other topics, among diverse populations.

Keywords

Ecological systems theory · Event history analysis · Life course theory · Life History Calendar method · Qualitative social research · Social pathways

1 Introduction

In response to many of the challenges that arise from studying individuals as they age and progress through various stages of development – from childhood into adolescence, adulthood, and beyond – the interdisciplinary life course framework emerged in the late 1990s and has spread across many social science and health-related fields (Elder et al. 2015). The concept of the life course refers to a series of age-graded events and roles that shape the individual's biography and are, in turn, shaped by both micro- and macrolevel social contexts. Although longitudinal panel studies comprise the gold standard in life course research, logistical matters often limit the viability of large-scale data collection over time. Thus, researchers have worked to develop valid and reliable methods of collecting retrospective life course data that capture the ways that biography, history, and social contexts interact to influence development over time.

The Life History Calendar (LHC) has emerged as one key method for gathering reliable retrospective event timing and sequence data for quantitative life course studies. In this method, researchers use a preprinted matrix, with time cues running horizontally across the page and topic cues running vertically down the page, to help respondents piece together their past. The grid aids event recall because it matches the structure of autobiographical memory and improves data quality because researchers can easily pinpoint omissions and contradictions (see also ► [“Calendar and Time Diary Methods”](#)). Its highly structured format, however, does not permit researchers to capture explanatory data on why or how the respondent's life story has unfolded as it has. Because of the need for detailed contextual data in qualitative life course research, I developed a semistructured adaptation of the LHC.

The semistructured LHC discussed in this chapter builds on Martyn and Belli's (2002, pp. 271–272) assertion that life history calendars “could be used in qualitative research to stimulate discussion about past experiences and underlying processes that help explain behavior, attitudes, and emotions.” As such, this methodological innovation incorporates research participants' attitudes and aspirations, interpretations, and explanations of life transitions and major events that would not be captured in standardized event histories. By merging the characteristic detail across multiple domains of the traditional LHC with in-depth narrative, the semistructured LHC method achieves nuanced longitudinal narratives. In this chapter, I review the history and evolution of the LHC, as well as practical advice for implementation of a semistructured LHC protocol for qualitative research in the social sciences.

2 Life Course Theory

The tradition of life course research highlights the interplay between cultural background, social ties, human agency, and timing (Giele and Elder 1998). These factors intertwine such that individuals' actions and attitudes depend not only on microlevel situations (e.g., parent-child interactions) and macrolevel structures (e.g., federal policy) but also on historical context and individuals' constructive activity (Bronfenbrenner 1979; Mortimer and Shanahan 2003). Thus, life course theory serves to unite ecological systems theory (Bronfenbrenner 1979; Bronfenbrenner and Morris 2006) with a temporal approach (Elder 1974). In contrast to psychological approaches that tend to parse out distinct facets of the developing individual, such as emotion, cognition, or motivation, life course theory views each person as a dynamic whole playing an active role in his or her own development (Elder et al. 2015). Although we experience personal agency, our choices are always constrained by the pathways made available to us by historical and social circumstances. For example, the career choices available to women in New York City during the 1950s were markedly different than the career options available to women in rural Oregon during the same time period, and both sets of choices are different from the options available to American women in the 1990s. Social pathways, a key concept in life course theory, are defined as age-graded sequences of social positions that reflect the macro- and microlevel contexts of development.

Developmental psychologists have often used Bronfenbrenner's ecological systems theory (1979) and expanded bioecological theory (Bronfenbrenner and Morris 2006) as a framework for examining human development. Ecological approaches to development argue that context matters. Early iterations of the theory positioned the individual at the center of four contextual layers – much like the smallest piece in a set of Russian nesting dolls – through which each plays a key role in development. The first layer – the microsystem – refers to face-to-face settings where a person spends time, such that each setting (e.g., home, classroom, and workplace) comprises a distinct microsystem. The next layers contain connections between microsystems – with mesosystems comprised of linkages between settings that include the individual in question, and exosystems comprised of linkages between microsystems where one does not include the individual. For example, the interaction between a parent's work schedule and their child's ability to participate in an after school club is part of an exosystem for the child as one of these settings – the parent's work – does not include the child. Meanwhile, the interaction between the child's school and the after school club are of part of the mesosystem, as both settings include the child. These three layers of context – microsystems, mesosystems, and exosystems – are all nested within a macrosystem, which is comprised of societal beliefs and values.

Recent iterations of ecological theory recognize more than just context and argue that development is the product of multiple layers of context interacting with person, process, and time (Bronfenbrenner and Morris 2006). Person refers to individual-level characteristics, including social identities such as age and race, and developmental traits like temperament and personality. Process refers to individuals' experiences within a microsystem or the ways that person and context transact. Finally,

time refers to minute-by-minute exposure to processes within microsystems, duration of participation in a given microsystem, and historical changes in society across generations.

Life course theory brings together Bronfenbrenner's conception of multilevel social context with sociological understandings of the life course as a pattern of age-graded events and roles. Life course theory positions human development as a life-long process situated in historical time and place and compelled by human agency. This framework highlights the ways that the timing of particular events and transitions drives cumulative effects over time, by underlining the importance of transitions (i.e., exit from one role and entry into another) and turning points (i.e., marked shifts into new behavioral patterns). While focusing on the ways macro- and microlevel factors shape social pathways, and individuals' behaviors and achievements over time shape their own trajectories, life course theory also recognizes the ways that relationships with significant others play a role in development. Specifically, the principle of "linked lives" highlights how social networks exert informal social control and how intergenerational transmissions contribute to the social reproduction of education, occupation, and beliefs. Research on the life course is becoming more prominent across various fields of study (Mortimer and Shanahan 2003), including the health social sciences.

3 The Life History Calendar

The Life History Calendar (LHC) is ideally suited to life course research as it is designed to situate the study of individual agency within multiple social contexts and historical time. The traditional LHC is a preprinted matrix with time cues organized horizontally and domain cues relevant to the study running vertically. Researchers may partition temporal cues into months, years, or any time unit appropriate for the study at hand. Domain cues refer to indicators, such as births, marriages, living arrangements, and educational transitions, and vary according to each study's intention. The LHC may be completed by the interviewer (in person or via phone), or filled out by the respondent (Furstenberg et al. 1987; Freedman et al. 1988; Mortimer and Johnson 1999). The LHC not only spotlights processes of engagement in and disengagement from activities, groups, and behaviors – thus exposing human agency – it also uncovers patterns of behavior over time, thus revealing continuity and change (Laub and Sampson 2003). In addition, the LHC exposes the heterogeneity of behaviors across a population that may lead to a common outcome, helping researchers to unpack complex phenomena (Laub and Sampson 2003). Finally, this approach brings to light the ways that individuals' behaviors are the product of social and historical contexts and the ways that those contexts and individuals' reactions to them change over time (Laub and Sampson 2003).

The LHC has emerged as a reliable method for collecting retrospective data on multiple simultaneous event histories and offers various benefits during the data collection process (Freedman et al. 1988; Belli et al. 2009). Use of the matrix has been shown to ease respondents' event timing recall (Freedman et al. 1988; Caspi et

al. 1996), as more memorable events, such as the birth of a child, act as reference points that help subjects accurately place the timing of less memorable events, such as job changes. The visual nature of the matrix also supports event recall (Meltzer 2001), while providing respondents an opportunity to reflect on their own experiences (Feldman and Howie 2009). Furthermore, the LHC provides a simple format for recording detailed sequences of events (Freedman et al. 1988), allowing interviewers and participants to identify gaps and contradictions within each event history. For example, by mapping marriages chronologically, the interviewer can confirm that marriage and divorce dates for a first marriage do not overlap with dates given for subsequent marriages.

In addition, studies have shown that the LHC method elicits more accurate retrospective data than traditional questionnaires (Belli et al. 2001; Van der Vaart 2004; Van der Vaart and Glasner 2007; Yoshihama et al. 2005). Two studies find at least 90% agreement between retrospective reports of activities for a given month on LHCs and concurrent reports obtained 3–5 years earlier (Caspi et al. 1996; Freedman et al. 1988). Belli (1998) posits that LHCs promote accuracy because they map to the structures of autobiographical memory. Both the calendar and the human mind activate recall through multiple pathways: in time order within a life theme and across parallel themes involving simultaneous or sequential events. While survey questions tend to segment related aspects of autobiographical events, LHCs actually draw upon the interrelatedness of events to improve recall and accuracy (Belli 1998). LHCs improve data quality by providing visual and conversational cues that cater to the way the brain retrieves information and improving cognitive and conversational engagement (Belli et al. 2004).

Since its inception, the LHC has been used primarily for large-scale quantitative studies (Axinn et al. 1999). One of the earliest uses of the LHC was in a large-scale study examining race and the timing of education, employment, and family events (Blum et al. 1969). Since then, the LHC methodology has been used to study myriad topics, including many relevant to the health social sciences: adolescent transitions to adulthood (Freedman et al. 1988), psychopathology (Kessler and Wethington 1991), marital transitions (Thornton et al. 1992), organizational dynamics (McPherson et al. 1992), drug dependence (Hser et al. 1997), couples' social relations (Munch et al. 1997), agricultural chemical exposure (Hoppin et al. 1998), domestic violence (Yoshihama et al. 2002), sexual behaviors (Martyn et al. 2006), and welfare transitions (Harris and Parisi 2007).

4 The Evolution of the Life History Calendar

Like any methodology, the Life History Calendar (LHC) demands careful implementation and, often, updates and alterations. One of the first methodological articles on the quantitative LHC examined a sample of 900 young people between ages 15 and 23, born in the same city during the same month (Freedman et al. 1988). The article highlighted implementation considerations, such as: specifying time units, identifying domains, streamlining use of symbols, and designing an easy to use

matrix. It also cited logistical complications including the ways the size of paper, tables, and clipboards used for each calendar impacted data collection procedures (Freedman et al. 1988). The common birth month and location, as well as the respondents' young age, however, spared these researchers from some of the logistical difficulties that other scholars would subsequently encounter.

In their study of farmworkers, Hoppin et al. (1998) introduced a number of modifications to the LHC to accommodate older respondents and increased age diversity within their sample. These researchers increased the time unit on the preprinted matrix from months to years, which allowed more room on the page for larger numbers of years of lived experience. In casual interviews prior to beginning the formal study, the authors noticed that respondents used world and personal events to recall farm events. Thus, through focus groups, Hoppin et al. identified world events that were relevant to their sample – such as elections and wars – and preprinted those events on the LHCs used during formal interviews. Having landmark events spaced evenly across time aided recall for older participants, as life events – such as graduations, marriages, and births – tended to cluster together. The inclusion of landmark events has since become common practice in LHC research. Notably, Hoppin et al.'s use of the LHC to study employment histories has been adopted by the field of occupational epidemiology, where this methodology has become known as the Occupational History Calendar. Several studies in this field have corroborated the utility of the Occupational History Calendar in capturing complex work histories among the general public (Lilley et al. 2011) and among special populations such as migrant farmworkers (Zahm et al. 2001).

In their study of rural Nepalese communities, Axinn et al. (1999) revised the standard LHC to accommodate culturally situated notions of time. Their study included multiple temporal cues: the Western year, the year on the local calendar, the animal year, and a blank line for the respondent's age. In addition to including world events identified by focus groups, the authors included local "landmarks" as identified by neighborhoods (Axinn et al. 1997). Further, the matrix and recording symbols were modified to accommodate culturally acceptable behaviors, such as the practice of having multiple spouses simultaneously (Axinn et al. 1999). These innovations opened the door to large-scale event history analyses with populations that do not adhere to Western time-keeping conventions.

Such adaptations of the LHC have improved the methodology and diversified its uses, yet these modification have done little to illuminate the processes of individual decision-making in the context of life transitions (Harris and Parisi 2007). To understand how personal circumstances might play a role individuals' interactions within the welfare system, Harris and Parisi (2007) paired the traditional LHC with a series of open-ended questions and analyzed responses using qualitative data analysis techniques. The authors found that open-ended questioning exposed nuanced circumstances leading to welfare entry and helped interviewers engage more openly with respondents. In one example, the authors identified two women with similar LHCs, yet open-ended questioning revealed that the women had led decidedly different lives. Thus, Harris and Parisi were able to overcome one of the key limitations of the traditional LHC by adding open-ended interviewing to the standardized protocol.

Respondents' explanations, however, were still bounded by the categories established on the preprinted matrix. Although limiting the categories of response eases data coding, entry, and analysis, and thus may be desirable in quantitative or large-scale studies, qualitative research depends upon the breadth and depth of respondents' narratives being unhindered by researchers' preconceived categories. Therefore, the very nature of the preprinted matrix contradicts one of the primary goals of qualitative research. By developing a life history protocol that does not rely on a preprinted matrix, I bring many of the advantages of the LHC method to qualitative research.

5 Adapting the Life History Calendar for Qualitative Studies

Initial development of the semistructured Life History Calendar (SSLHC) method for qualitative research occurred within a longitudinal study exploring how afterschool programs and extracurricular activities might influence working class and poor Mexican American students' pathways to college (Nelson 2017). Interviews had been conducted while respondents were eighth grade students (approximately age 12), and the Life History Calendar (LHC) method was adapted for use during follow-up interviews with the same respondents during their young adult years (ages 19 to 22). All respondents attended the same urban California middle school and continued to reside within a 1-hour drive of that school at the time of the follow-up interviews. Ten of the twelve respondents were Mexican or Mexican American and nine were female. Approximately 40% of the respondents attended college full-time, while the remainder attended community college or trade school intermittently or part-time. Each young adult interview lasted an average of 2 hours.

I began the project by pilot testing a structured LHC protocol coupled with open-ended questioning, as described by Harris and Parisi (2007), among a population of 18- to 22-year-old full-time college students from working class or poor family backgrounds. Pilot interviews, however, failed to elicit in-depth responses; instead, participants interpreted the structure of the matrix as a signal to limit their responses to event timing information and only shared events that fell within the domains preprinted on the matrix. During semistructured interviews conducted immediately after the LHC was completed, respondents revealed critical life events that were not explicitly part of the matrix. Such events were influential in their educational trajectories, yet the preprinted matrix had not left space for events outside the domains predetermined by the researcher at the onset of the study. For example, one participant spoke about her transition from living with her birth parents to a foster family; although residential moves were accounted for on the LHC, the motivation for the moves was not. In this case, the change of guardianship would have been a critical life event omitted from the respondent's biography because of the structure of the LHC matrix. Another participant spoke about the deportation of a parent by immigration authorities during his elementary school years. Since this change was not accompanied by a residential move, it too was omitted from the structured LHC. Since the goal of my research was to generate in-depth qualitative

data that accounted for all of the influences on students' educational pathways over time, I began pilot testing less structured adaptations of the LHC.

After multiple rounds of pilot testing, each with less structure to the matrix than the previous, I determined that the most detailed data emerged from the interviews I had begun with a blank page. The respondent and I subsequently coconstructed time cues horizontally – from birth to present day – and domain cues vertically. Due to the age of my respondents, I determined that school experiences and home life should each constitute one domain and drew a line representing school events and relationships across the top of the page, and a line representing home events and relationships across the bottom of the page. I indicated to the respondent that the middle band of the page could be used for extracurricular activity participation (the topic of interest in this particular study), as well as any other relationships, experiences, or events. This provided each respondent with a designated space to include topics that fell outside the predetermined domains. How respondents filled this space varied dramatically and underscored the importance of moving away from a preprinted matrix. Instead of pencils, interviewers and respondents used colored markers and children's stickers to map out the respondent's life course. See Fig. 1.

This semistructured LHC (SSLHC) method has many of the same benefits as the traditional LHC, including mapping out processes of engagement in and disengagement from activities, groups, and behaviors; exposing patterns of behavior over time; and bringing to light the ways that individuals' behaviors are the product of ever-changing social and historical contexts. The SSLHC also relies on the matrix format

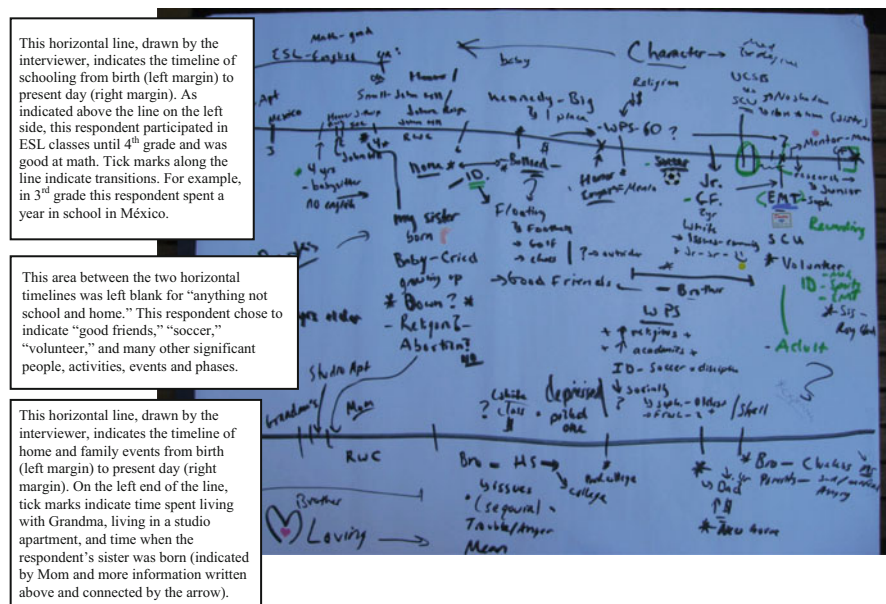


Fig. 1 Sample LHC adapted for qualitative research

to ease respondents' event timing recall and provide a simple format for recording detailed sequences of events. In addition, the SSLHC elicited in-depth longitudinal narratives.

One benefit specific to the SSLHC method stems from the fact that the respondent is empowered to take ownership of the interview by dictating the order in which topics and time periods are discussed and the way in which the matrix is constructed. Rather than taking charge of which questions were asked and in what order, the interviewer's role consisted of outlining the parameters of the interview – including time periods and topics of interest – giving the respondent permission to begin with any topic and time period, then following up with probing questions as the respondent narrated their own life course. The SSLHC scaffolds the interview by acting as a visible reminder of which fields and time periods have been covered and which have yet to be explored, and the domain cues prompt respondents to nest their educational trajectories in context. Because respondents were not confined by narrow lines of questioning, they were empowered to talk about their lives by highlighting the events, people, and places which, in their view, were most significant.

This adaptation of the LHC provides a specific benefit to researchers studying emotion-laden topics. Because the respondent directs the sequence of the interview, the interviewer and the respondent tended to develop a strong rapport that encouraged elaborated narratives. Furthermore, since respondents begin with any time and domain, respondents may delay speaking about emotionally challenging experiences until they have settled into the interview and feel more comfortable with the interviewer. During my pilot study, respondents consistently opted to begin recounting their lives with narratives of times during which they felt successful and delayed recounting difficult periods. For example, one respondent who immigrated from México as a young child and was in eighth grade when her mother died, chose to begin the interview with her elementary school years, followed by her time in high school, and returning to her early childhood and middle school years – her most trying times – near the end of the interview. Since interviewers cannot know which periods of a respondent's life were most difficult prior to embarking on the interview, letting the respondent to dictate his or her own sequence of events, within the structure of the SSLHC matrix, provides researchers with an opportunity to establish rapport early in the interview, thus positioning themselves to capture vivid and valid narratives of emotionally sensitive events. For this and other reasons, Carpenter (2015, p. 75) posits that scholars researching sexualities over the life course may find the semistructured LHC method “particularly helpful.”

Another benefit of the SSLHC method is the ability to offer open-ended domain fields, thus capturing events and relationships outside the researcher's preconceived notions of what might be important. In the case of my study, I designated the center section of the page for “anything not school or home,” opening the matrix up for unlimited potential topics. For example, one respondent's recalled a time during his elementary school years when his mother was pregnant and feared the baby would have Down syndrome. The pregnancy was a turning point in the respondent's trajectory because it brought his family together and strengthened their religious practice. The subsequent birth of a healthy child prompted the family to become

even more enmeshed in their church community and steered the respondent toward private Catholic schools. Standard questionnaires recounting students' pathways to college likely would have recorded that this respondent attended private Catholic schools and that those schools influenced his decision to apply to and attend a competitive religiously affiliated university. Standard questionnaires, however, likely would not have captured the influence of his mother's pregnancy.

Since the development of the SSLHC for qualitative research (Nelson 2010), this methodological innovation has been used in various studies across social science and health-related fields. For example, Thompson (2015) used the technique to develop case studies of individual students as she investigated the costs and benefits of being labeled a long-term English learner (LTEL). In her study, each respondent completed the SSLHC during their first interview. The respondent's parent subsequently added to and modified the SSLHC during their interview. Finally, the respondent reflected on and updated the SSLHC in a follow-up interview. In another example, Smith (2015) referred to her SSLHCs as "chronologies of loss," as she used the technique to study the frequency and timing of homicide deaths across the life course among low-income Baltimore adolescents and young adults. Vermeer et al. (2016) adopted the SSLHC method to study sexual dysfunction and psychosexual support among cervical cancer survivors and their partners, adding disease diagnosis as a timing cue in addition to calendar time. Reisner et al. (2016) used the SSLHC method to explore sexual and gender development in a pilot study examining STI and HIV prevention interventions among transgender men. Rimkeviciene et al. (2016) utilized the SSLHC to study the timeline of events leading up to suicide attempts. Each of these studies supports the utility and flexibility of the SSLHC method for qualitative research.

6 Implementation

In the sections that follow, I provide logistical advice on implementing the semi-structured Life History Calendar (SSLHC), including the selection of time cues and landmarks, domain cues, starting points, materials, and data entry and analysis.

6.1 Time Cues

Time cues vary across studies and should be adapted to fit the goals of each research project. Cues can include Western or non-Western calendar time, age, educational, or employment landmarks, health or disease-related markers, or any other unit of time or combination of time cues the researcher and respondent deem relevant. Due to the age of the respondents in my study of educational trajectories (Nelson 2017), I employed school transitions as the most salient "landmarks" across the temporal line of the SSLHC (Axinn et al. 1997; Hoppin et al. 1998). Thus, the matrix, like the interview questions, was divided into five sections: before elementary school, elementary school, middle school, high school, and after high school. Since not all participants started elementary school on time or completed high school, it made sense to begin the

interview with a blank page and add the school landmarks in the presence of the interviewee. For example, one respondent moved to USA at the age of 7 and began school in the second grade. Prior to that time, she had not attended school. Another respondent dropped out of high school after tenth grade when his girlfriend gave birth to their son. In his case, the “after high school” section began at age 16. In Vermeer et al.’s (2016) study of cancer survivors’ sexual experiences, time cues were constructed relative to disease diagnosis rather than across the entire life course, including “1 year before diagnosis; diagnosis; treatment; 3, 6, and 12 months after diagnosis; until 5 years after diagnosis” (p. 1680). In Rimkeviciene et al.’s (2016) study of suicide attempts, the researchers used the attempted suicide as the end point of the timeline and allowed the respondent to fill in the important events in their life that led up to the attempt.

6.2 Domain Cues

Domain cues, like time cues, were introduced by the interviewer at the onset of the interview and were not preprinted on the page. The domains for my study were: school (across the upper third of the page), home and family (across the bottom third of the page), and “everything that’s not school and not home” (across the middle third of the page). This final category was intentionally open and helped to record many idiosyncratic events across interviews. My intended purpose for this domain was to capture extracurricular activities, including sports, paid work, and community programs, yet this section provided space for other topics as well, such as religious involvement, gang affiliations, and chronic illnesses. By leaving this domain cue open to interpretation, the category was not limited to my conceptualization of extracurricular activities, and the SSLHC served to capture a variety of meaningful events and experiences. O’Connor et al. (2015) posit that this open-ended approach allows the researcher to shift from a variable-centered approach to a person-centered approach and provides a better understanding of why individuals follow different trajectories.

Other studies, based on the topic of interest and the age of the respondents, have used other domain cues. In their study of cervical cancer survivors, Vermeer et al. (2016) used work, relational status, holidays, disease and treatment, sexual functioning and received information and care as their domain cues. They also included an open-ended domain cue – important life events – to leave room for respondents to tailor the calendar to their own experiences. Smith’s (2015) study of homicide among young adults relied on one primary domain cue – death-related loss. Similarly, Porcellato et al.’s (2016) study of employment used work experience as the only domain. Like time cues, domain cues can vary in content and quantity, as applicable to the study at hand.

6.3 Starting Point

Respondents were invited to dictate where they wanted to begin their life history. Some opted for a chronological approach starting with birth, others began at the present day and worked backwards, and some skipped around in time, as described

earlier in this chapter. This flexibility gifted respondents with ownership of the interview and license to begin where they felt comfortable. Generally, respondents chose to begin at the time furthest from their most difficult years. By integrating the SSLHC and interview questions, the scope of the interview was apparent to respondents, thus both the interviewer and respondent could monitor which periods of life had yet to be covered regardless of where the interview began. Others who have implemented this methodology have adopted a similar approach. This flexibility, enabled by the coconstructed matrix, stands out as one of the unique features of this methodology.

6.4 Materials

As in previous incarnations of the LHC (Freedman et al. 1988), I found the size of the paper to be important. In pilot interviews, respondents began to truncate their responses when the paper appeared to be full; the larger the paper (and the more blank space), the more detailed the respondents' answers became. In my first pilot interviews, I used a standard letter size paper (8.5 × 11 in.), then grew to a legal size (8.5 × 14 in.), and then to subsequently larger and larger sizes of drawing paper. Ultimately, I settled on a standard easel pad (25 × 30 in.) consisting of large, high-quality paper with a cardboard backing. The sturdiness of the cardboard backing made the paper easier to transport to interviews and suitable for use even on smaller-sized tables. The size of the paper, however, had implications for the location of the interview. Ideally, the SSLHC matrix would sit on a table facing the interviewer and respondent so that both can add to the calendar easily and write right-side-up. Libraries and conference rooms proved to be suitable locations as they often contained larger sized tables.

In my study, the respondent and interviewer coconstructed entries on the SSLHC using colored markers and children's stickers. To indicate length of involvement in an activity, organization, or relationship, I drew horizontal lines with a vertical tick to indicate starting and stopping points. Although others have standardized color codes and symbols (e.g., Freedman et al. 1988), I allowed the respondent to use colors, symbols, and stickers freely. Rather, the interviewer and respondent employed symbols that resonated with the respondent. For example, if a respondent lived with her mother and two sisters she might write "M + 2S" at that point on the calendar, or she might draw stick figures instead. One respondent indicated a difficult period during high school by drawing a cloud around that entire period on the SSLHC. Granting each respondent permission to use colors, symbols, and words in their own fashion allowed respondents the freedom to express not only events in their lives but also their reactions and interpretations of those events. This kind of expression and interpretation cannot be achieved on the traditional LHC. See Figs. 2 and 3.

Stickers were another tool which helped some respondents engage with the LHC protocol. I offered respondents a variety of stickers representing different activities, events, affiliations, places, people, and animals. As with the colored markers, I did not prescribe each sticker a meaning; I offered the stickers to respondents at the beginning of the interview and encouraged them to place stickers along the calendar

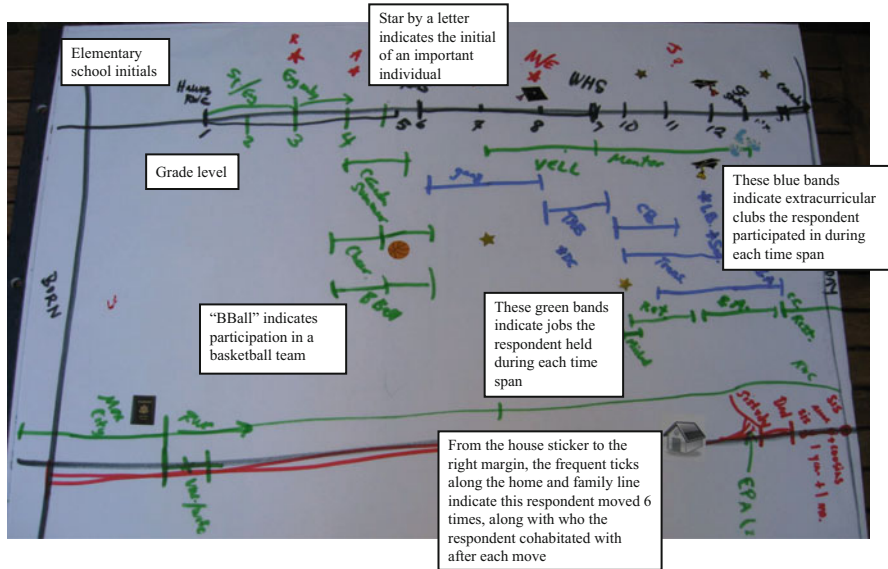
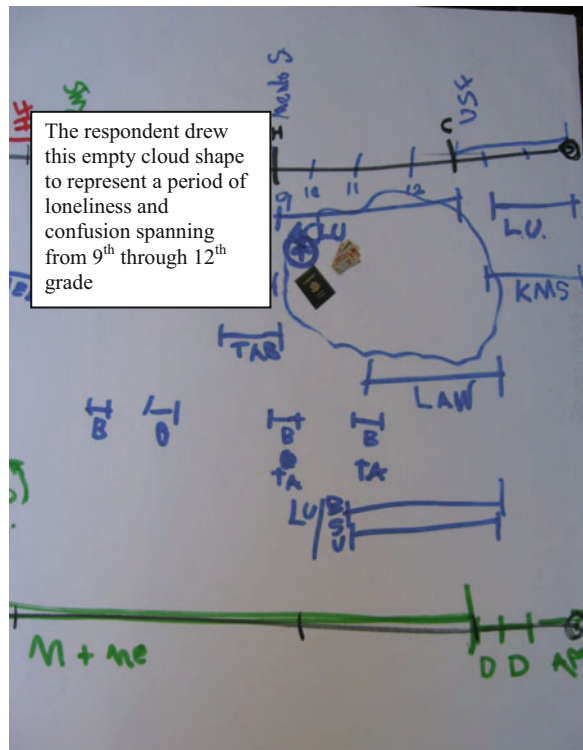


Fig. 2 Sample of adapted LHC symbols

Fig. 3 Sample of interpretation of life events



as they saw fit. Many respondents used the stickers in a traditional way – if they played soccer in middle school, they used a soccer sticker, or if they studied to be a doctor, they used medical stickers. Other respondents used stickers to creatively signify life events. For example, while answering a question about elementary school, one respondent began sticking medical stickers in the high school section of the SSLHC next to a house sticker with black bars across it. I did not change the course of the interview, but when she began talking about high school I inquired about the stickers. The respondent revealed that when she was a high school student she had been addicted to drugs. She then locked herself in her house for many months in order to kick the habit (see Fig. 4). Another respondent piled on suitcase and passport stickers near the end of the high school section of the SSLHC. She reported she had been on a trip abroad at that time which had changed her life. To this respondent, a larger quantity of stickers came to indicate a more influential event.

Some respondents, particularly young men, did not choose to use stickers, and it is likely that stickers may be more useful for some respondents than others. Even when respondents chose not to use stickers during the interview, however, the

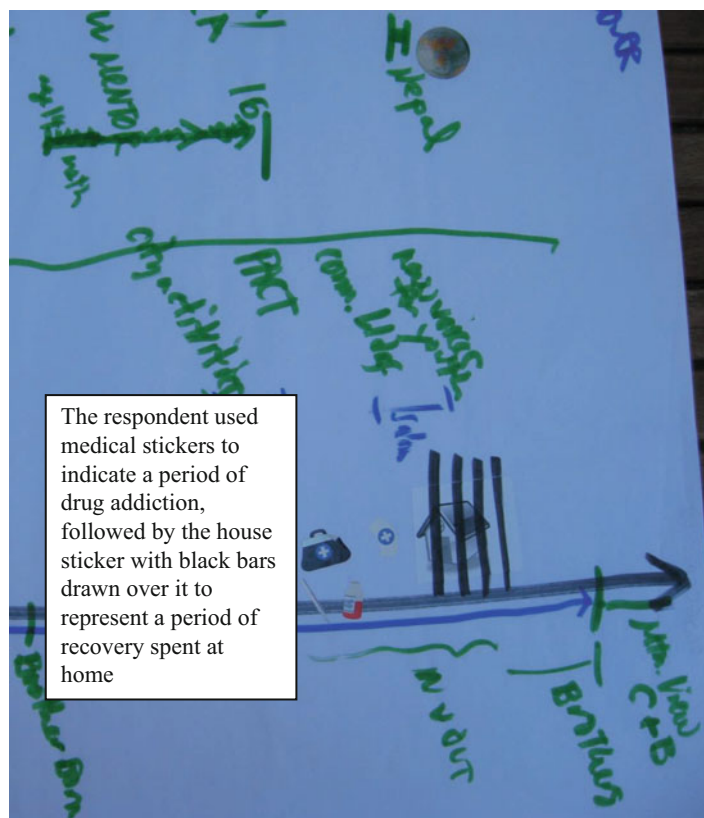


Fig. 4 Sample of use of stickers

interviewer's introduction of the stickers helped break the ice and establish rapport. Many respondents noted that having stickers (even if they did not use them) brought back images of elementary school and helped set the mood for conversations about their childhood. Overall, the stickers enabled greater participation for some and improved rapport for all respondents. While other researchers have used stickers to indicate specific events on a traditional preprinted LHC matrix (e.g., Hoppin et al. 1998) or occupational history calendar (e.g., Porcellato et al. 2016), the open-ended use of stickers lends itself particularly well to the SSLHC.

6.5 Data Entry and Analysis

The primary source of data used for analysis was the transcribed audio recording of each interview. The purpose of the SSLHC was to collect both event timing information and individual explanations of behaviors and attitudes, nested within overlapping social contexts. As such, the SSLHC was an effective tool for easing retrospective recall, building rapport between interviewer and respondent, and easily checking to make sure all desired time periods and domains had been covered during the interview. Beginning with a blank page and allowing respondents to coconstruct their matrix using markers and stickers supports these goals. But because each respondent created a unique system of symbols and colors, the SSLHCs were of limited analytical use. Although this incarnation of the SSLHC method succeeds at providing in-depth interview narratives, it does not offer the same ease of data entry as preprinted LHC matrices.

7 Conclusion and Future Directions

In recent years, the semistructured adaptation of the Life History Calendar (SSLHC) for qualitative research has been used to study a range of topics across health- and social science-related fields. This adaptation allows for many of the same benefits of the traditional LHC. Yet, unlike the traditional LHC, the SSLHC captures not only the starting and stopping of activities but also the how's and the why's behind each transition. This coupling of event timing with explanatory data provided more nuanced insights into marginalized students' pathways to college than either the structured LHC or qualitative interviewing could produce independently. For example, when a respondent reported changing schools at the end of third grade without a housing move, the SSLHC captured both the change and the explanation:

We had this. . .Oregon Trail project and. . .the teacher assigned each one of us to be a pioneer. I told [the teacher] that I didn't think that this game or simulation was a fair representation. What about the Indians? And. . .that was not part of her happy pioneer project. I was totally defiant. I said I didn't want to participate and I didn't want to be a pioneer because they killed the Indians and they exploited them and I didn't think it was doing justice and we weren't representing all parties involved and representing it historically accurately. I didn't want to participate. So in the end, we had 19 pioneers and one little Indian. It was just a big fight. From then on. . .well it was time I went to a different school.

In this case, as in many others, the cause of the school transition is more meaningful in her overarching educational trajectory than the transition itself. Although frequent school changes are one predictor of academic failure among Latina/o students, it is assumed these changes are the product of household disruptions or residential moves. This example suggests why understanding the cause of the move is critical to understanding whether the change of schools might have positive or negative consequences within an individual's educational trajectory.

My study highlighted many examples of how the SSLHC produced invaluable explanatory data in tandem with in-depth interviews. For instance, one respondent stopped participating in extracurricular activities at the time of her mother's death. In the traditional LHC method, researchers might assume the respondent discontinued participation due to grief. However, the SSLHC brought to light that her change of routine was only indirectly attributable to her mother's passing. In her traditional Mexican family, this respondent was now the oldest female and – at age 12 – was expected to take on the family's cooking, cleaning, child care, and shopping. The increased level of responsibility at home accounted for her subsequent lack of participation. Given the tendency in the current literature on Latina/o students to model pathways to college as straight lines, predicted by easily operationalized variables, the SSLHC has the potential to further nuance both research and theory.

While the SSLHC method is likely not well suited to large samples due to the potential complexity of data entry and coding, this method shows promise for life course research with smaller samples across a variety of fields. For example, O'Connor et al. (2015) posit that this qualitative life history method offers an important complement to statistical modeling in the study of individual trajectories in the field of clinical psychology. The authors argue that even the most sophisticated trajectory models adhere to inappropriate assumptions about human behavior and suggest a paradigm shift toward thinking about transitions and turning points within a person-centered approach using the SSLHC to begin identifying key life events. O'Connor et al. (2015, p. 20) write:

The life calendar method of Nelson (2010) offers a key to anchoring recall in key landmark events, rather like squares on a game board. The person is likely to recall their detailed experiences around these key points. One could then calculate the most likely events that were concurrent with the turning point, including cognitive and emotional reactions to outside events, and identify the a posteriori likelihood of the early patterns reported as early transition points reflecting current patterns.

In clinical psychology, the SSLHC stands out as a particularly useful methodology because it situates data on turning points within overlapping social contexts. Carpenter (2015) posits that the qualitative LHC may prove particularly useful for sexualities researchers as well, because the nature of the matrix facilitates recall of both highly salient events and less salient events that may play a role in an individual's developing sexuality across the life course. These are just two examples in a world of possibilities of how the SSLHC may prove useful for life course research across a variety of fields in the years ahead.

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Calendar and Time Diary Methods

69

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Contents

1	Introduction	1220
2	Time-Use Research	1221
2.1	A Brief Historical Account of Time-Use Research	1222
2.2	A “New” Paradigm to Measure Well-Being	1223
3	Well-Being and Surveys: Calendar and Time Diaries as the Tools to Measure Well-Being	1224
3.1	The Role of Flexible Conversation Techniques in Reducing Error in Timeline Surveys	1225
3.2	The Role of (Autobiographical) Memory in Reducing Error in Timeline Surveys	1226
4	Applying Time Diary and Calendar Methods to the Analysis of Well-Being	1228
4.1	The Currency of Life: Measuring Well-Being Through the National Time Accounting Framework	1229
4.2	Event History Calendar Methods to Assess Health-Related Issues	1231
5	Conclusion and Future Directions	1233
	References	1234

Abstract

For decades, individual and social well-being have been reduced to material well-being. Given that economic or financial success cannot fully capture an integral concept of human well-being, a new paradigm has emerged, one which focuses on the nonmarket contribution and behavior of households. This new paradigm goes

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beyond the typical scope of economic science in which only the activities that can be measured in monetary terms are included. A critical aspect of this paradigm is that the way people spend their time needs to be taken into account in a rigorous and scientific way, as it is only by understanding previous life events that present and future life course development can be predicted. Thus, valid retrospective and behavioral reports are needed from individuals. When the goal, however, is not only to conduct qualitative research (e.g., through in-depth interviews), but to draw quantitative inferences from samples to the general population, survey interviewing is inevitably involved. In this chapter, we will examine calendar and time diary methods which have been shown to be especially effective when it comes to assessing well-being. Although these methods forego the standardization of question wording (the most prevalent approach in traditional survey interviewing), they are nevertheless able to produce reliable and valid responses, while also encouraging conversational flexibility that assists respondents to remember and correctly report the interrelationships among past events. Further, in this chapter we also discuss the application of the calendar and time diary methods in several health and social sciences fields of research, through which well-being is evaluated.

Keywords

Calendar method · Time diary method · Time-use research · Well-being

1 Introduction

One key concern of behavioral, social, and health scientists is to assess people's well-being. Within the field of modern economics, national income statistics such as the Gross National Product (GNP) and the Gross Domestic Product (GDP) have not only been looked upon as reliable measures of economic success or failure, but also have increasingly been thought of as measures of societal well-being (Stiglitz et al. 2010). During the 1980s, a growing number of voices (economists and social scientists alike) have expressed discontent with the notion that an increase in GDP could be equated with an increase in well-being (e.g., see Juster and Stafford 1985). The creation of a Commission to “measure economic performance and social progress” in 2008, spearheaded by the economist Nobel laureates Joseph Stiglitz and Amartya Sen, is a clear sign of such a dissatisfaction. Its main recommendations included emphasizing the household perspective and broadening income measures to nonmarket activities. Although the Commission's creation was a highly visible initiative within the international political arena, the topic was not new. Indeed, the idea of devising an augmented system of economic and social accounts that would recognize the nonmarket activities of households had already been proposed decades before (Juster 1985). Understanding how people spend their time is at the heart of such an endeavor (Stiglitz et al. 2010).

In this chapter, we argue that time-use research can provide hard and replicable data that reflect people's decisions, preferences, attitudes, and environmental

factors (Pentland et al. 1999), with which the many aspects of well-being can be assessed. In Sect. 2, we first discuss the developments of time-use research and we introduce a new paradigm to measure and analyze well-being. In Sect. 3, we discuss the need for well-being researchers to be able to draw quantitative inferences from samples to the general population through the use of surveys. We draw particular attention to time diary and calendar methods, as these constitute feasible alternatives to traditional ways of survey interviewing on well-being issues. The fourth section looks at ways in which time diaries and calendar methods have been applied to the measurement of well-being. We first look at the “National Time Accounting” framework to measure well-being through the use of the evaluated time-use approach. We then review some examples of how calendar methods have been used to assess health-related issues, arguably one of the most important predictors of well-being. In the final section, we present our conclusions and ideas for future directions.

2 Time-Use Research

The ability of time-use research to understand human behavior and its intrinsic relationship with individual and social well-being has been widely accepted and has garnered the interest of researchers from a broad range of disciplines including economics, gerontology, political science, nursing and medicine, psychiatry, health education and research, sociology, psychology, education, social epidemiology, criminology, demography, social work, and survey methodology (Pentland et al. 1999; Belli et al. 2009b).

Time-use research methods consist of both time diaries and “life histories” or event history calendars (calendars from this point forward). Both are similar in that they collect timeline data – for diaries the timeline is a 24-h day; for calendars it can range from months to years or even longer sections of the life course (Belli et al. 2009b; see also ► Chaps. 67, “Timeline Drawing Methods,” and ► 68, “Semistructured Life History Calendar Method”). Both diaries and calendars examine the allocation of time into different activities, including paid work, personal care, leisure, childcare, and, increasingly, a wide range of health-related behaviors by the different population groups (e.g., women, the elderly, persons with disabilities), at the daily, weekly, monthly, or yearly levels. During the first half of the twentieth century, the majority of time studies were conducted in the Soviet Union, Great Britain, and the United States, with some studies conducted in France, Germany, and Japan (For a detailed historical account of time use studies during the first half of the twentieth century see Pentland et al. 1999). Currently, almost every nation in the world conducts time-use studies of some sort, suggesting that from early on, researchers interested in examining those key events that govern people’s behavior, health, and social interactions have drawn on the study of how people use their time (Belli et al. 2009b). A brief historical account of time-use research follows.

2.1 A Brief Historical Account of Time-Use Research

Time-use research, in the form of diaries, emerged during the second decade of the past century in the context of early studies of the living conditions of the working class. That is, the original time-use research studies emerged as a response to industrialization and its ensuing pressures on people's daily lives. Interestingly, calendars also appeared in connection to social issues, specifically with the objective of investigating migration processes to the United States. The two first published works that gave an account of the daily lives of working-class families were published separately in the same year of 1913 in the United States and the United Kingdom (Bevan 1913 and Pember-Reeves 1913 cited in Pentland et al. 1999). These works, however, did not include systematically collected and representative data from diaries. The earliest sophisticated diary study belongs to the Soviet S.G. Strumlin, which was intended for use in governmental planning (Pentland et al. 1999). Several other smaller and isolated efforts were launched in Japan, the United Kingdom, and the United States, until the mid-1960s when Alensander Szlai launched a very ambitious program to systematically obtain time diary data from 13 countries around the world.

The first study where quantitative information coming from calendars was collected, processed, and analyzed dates from 1969, when the Argentinean Jorge Balán collected 1640 life histories of men aged 21–60 in Monterrey, Mexico. Before that, Thomas and Znaniecki (1918) had strongly advocated for an intensive use of life histories, but did not pursue systematic data collection because of insurmountable technical difficulties at that time. For Balán et al. (1969, p. 107), their ability to take advantage of “the possibilities opened up by large-capacity computers” (which, at that moment, involved the use of punch cards) made it possible to systematically analyze a large number of life histories. In the same year, researchers from Johns Hopkins University conducted the first calendar survey in the United States, which looked at socio-economic well-being (Belli and Callegaro 2009); specifically, its purpose was to empirically examine how social groups and individual households attained social mobility in order to identify alternative intervention directions (Blum et al. 1969).

Almost two decades elapsed before the next systematic study using calendars was conducted by the demographers Freedman et al. (1988). They sought to accurately measure the trajectories and event transitions that shape life course (Belli et al. 2009b) and especially to understand the processes that govern the transition from adolescence into adulthood. Freedman et al. (1988, p. 38) were able to estimate, through the use of sophisticated statistical methods, dynamic causal interrelations among several aspects of the life course, through which they concluded that the life course is not a unidimensional series of events unfolding, but a “simultaneous unfolding of many dimensions, all interwoven temporally and causally in complex ways.”

Many more studies came afterwards, which have shown that time-use research not only contributes to explain people's current condition, but also the long-term consequences of their daily decisions on their later well-being (Belli and Callegaro 2009).

2.2 A “New” Paradigm to Measure Well-Being

The time-use and well-being paradigm presented in 1981 by economists Thomas F. Juster, Paul N. Courant, and Greg K. Dow was the first formal conceptual system to measure and analyze well-being through the use of time. The key idea of their paradigm is that “the ultimate constraints determining the level of individual well-being are the availability of human time and the set of factors that determine the effectiveness with which time is used” (Juster and Stafford 1985, p. 1). Although they included material or intellectual resources in their set of factors, they also included the *capability* individuals have of enjoying and utilizing those resources throughout their life course, which is shaped by levels of physical and mental health.

This “new” social accounting system linking time-use and well-being develops from a long-established conceptual framework in economics that is based on the measurement of tangible resources. Monetary values are assigned to each element of the system and concepts such as wages, prices, profits, interest rates emerge. The new social accounting system appears as a general critique to that system and consists of three main critiques.

The first critique centers on the sole focus on flows of material goods and services, whereas well-being of individuals and societies is determined by the combination of available goods and leisure. In particular, the traditional economic welfare function, where leisure and goods are the only elements to be considered, lacks any appreciation for a positive connotation for time that is spent working: time at work is always a “bad” and only leisure time constitutes a “good” (Juster and Stafford 1985).

A second critique is that the traditional model accounts for the so-called “value added” to products at the different market stages (i.e., extraction, manufacture, and distribution), but expressly excludes any type of value added within the household. For instance, costs of manufacturing and distributing food are accounted for, but those costs related to the time spent in preparing (nutritious) food are not considered. Therefore, one of the main differences between both systems is that the social accounting system focuses not only on resource inputs, but on the changes in output. The result of incorporating a measure of the real output (such as a well-nourished family) allows for distinguishing between intermediate and final output (Dow and Juster 1985; Juster and Stafford 1991; Gershuny and Halpin 1996; Krueger 2009b). By avoiding an exclusive focus on resource inputs, the social accounting framework captures other phenomena that also impact well-being, but which traditional economic systems of welfare conceal. In sum, in the social accounting framework, material or “objective” conditions are “intermediate” outputs, while subjective measures are the “ultimate outputs” of interest.

Finally, the movement towards a more comprehensive system of accounts emerged from a deeper understanding of the concept of utility (Juster (1990, p. 156) reminds us of the original Benthamite concept of utility as the “cardinally measurable psychological flow of satisfactions attached to goods and services purchased in the market.”), which has provided the intellectual basis to incorporate the role of time in the measurement of well-being. From the social accounting

perspective, utilities do not just depend on the final product that results from a certain personal activity, but also on the *enjoyment* of the time spent in that activity. The theoretical implication is that the way the time is used – its level of enjoyment – needs to be taken into account (Juster et al. 1981; Gershuny and Halpin 1996; Krueger et al. 2009a, b). Hence, what becomes of interest are the so-called “process benefits,” that is, the extent to which a person actually enjoys the activity regardless of its price.

This new framework has been crucial for the measurement of well-being. It provides support for the creation of quality of life and social indicators and for the notion that goods and services are instruments for the (subjective) enjoyment of activities rather than ends in themselves. The “final output” can thus be registered by looking at indicators of subjective satisfaction with the various domains of life (Juster et al. 1985).

3 Well-Being and Surveys: Calendar and Time Diaries as the Tools to Measure Well-Being

Constructing a system with which to measure well-being entails understanding not only how people use their time but also how previous life events may predict future developments. For instance, evidence of the future detrimental consequences of tobacco use can be better supported with studies that look at the health status of smokers and nonsmokers who have been followed throughout a long period of time. Thus, time-use researchers need to have accurate information about the past and the present; that is, valid retrospective and behavioral reports from respondents. This ambitious goal cannot be based on qualitative research analysis (e.g., through in-depth interviews) that cannot be generalized. On the contrary, statistical-based analysis is needed for researchers to be able to draw quantitative inferences from samples to the general population. For that reason, interviewing a representative sample of the population is inevitably involved in such an endeavor.

Panels that use standardized methods and which follow a cohort across several year have been regarded as a reliable way of obtaining life course information. However, panels are costly, and thus other methods have been devised. Time diary and calendar methods have been proposed as feasible alternatives to traditional ways of survey interviewing, especially regarding different aspects of people’s well-being, including their emotional and physical health (Juster and Stafford 1985; Agrawal et al. 2009; Belli et al. 2009b; Belli and Callegaro 2009; Martyn 2009). Although these methods forego the standardization of question wording and encourage a more flexible interviewing approach, they are able to produce reliable and valid responses. Furthermore, calendar and time diary methods can be applied to a wide range of disciplines in health and social sciences research, allowing for a more systematic study of the many components of well-being.

The quality and validity of reports also hinge upon the way the information is collected. When studying the specific ways in which people use their time, conventional standardized questionnaires have been used. For instance, respondents may be

asked to estimate how much time they allocate to their different activities using a stylized list of activities. Yet it has been found that it can be very difficult for respondents to produce accurate responses using this approach and measurement error is likely to arise. From the time-use research perspective, two different mechanisms can be associated with error when using stylized questions: (a) the lack of flexibility that prevents the conversation to flow in a natural way (Jabine et al. 1984; Suchman and Jordan 1990), and (b) the fact that activity frequency and duration surveys using stylized sets of possible activities provide reports that are episodic and may be taken out of context (Pentland et al. 1999). Time diaries and calendar-based interviews, which ask about time-use using a conversational approach, have been proposed as an alternative to overcome such complications, mainly because of their ability to encourage respondents to incorporate in their cognitive processing temporal changes that serve as cues that assist providing a more accurate reporting of events (Belli et al. 2009b).

3.1 The Role of Flexible Conversation Techniques in Reducing Error in Timeline Surveys

Conventional standardized interviewing is the most widely practiced technique as it purportedly reduces variance in responses due to interviewers and maximizes variance attributable to the actual differences in respondents' circumstances (Fowler and Mangione 1990; Fowler and Cannell 1996; see also ► Chaps. 80, "Cell Phone Survey," and ► 81, "Phone Surveys: Introductions and Response Rates"). The first mechanism that may produce error in retrospective survey reports, namely the lack of conversational flexibility, can be attributed precisely to the standardization of the questionnaire. Time diary and calendar methods address this source of error by allowing interviewers to lead the conversation in a natural manner (Houtkoop-Steenstra 2000; Maynard et al. 2002). Although in conventional interviewing the *wording* of questions is standardized, there is no guarantee of a nonambiguous and consistent *understanding* of questions by respondents (Suchman and Jordan 1990; Houtkoop-Steenstra 2000). By assuming an interview is nothing more than a neutral measurement instrument, conventional standardized interviewing suppresses the elements of ordinary conversation, compromising both the understanding of the intended meaning and the validity of the answers.

Numerous studies have demonstrated how interviewers frequently cannot maintain the rules of standardized interviewing (Houtkoop-Steenstra 2000; Belli et al. 2001b, 2013). The conversational interviewing technique accepts that an interview involves an interaction between the participants, in which the rules of conversation must be respected (Schwarz 1996; Schwarz et al. 2009). Following Clark and Schober (1992), this technique recognizes that language is not about the literal meaning of words but about people and what they mean. The coveted goal of providing greater consistency to question meaning may be better reached by allowing interviewers to clarify the concepts and assist respondents when doubts of any sort arise (Schober and Conrad 1997; Conrad and Schober 2000).

Calendar and time diary methods take advantage of the conversational survey technique by disregarding the need to use fixed words and phrases and permitting flexibility to interviewers as long as they complete the diaries or the calendars in the way they are intended. The benefits to data quality due to the use of the conversational technique in diaries and calendars are further enhanced by the memory cues that are encouraged.

3.2 The Role of (Autobiographical) Memory in Reducing Error in Timeline Surveys

Answering survey questions necessarily involves cognitive and memory processes and their limitations are associated with error in survey reports (Belli 2013; Belli and Al Baghal 2016). For that reason, survey methodologists have incorporated cognitive science perspectives into their field of study (Jabine et al. 1984; Tanur 1992) (The initiative to incorporate cognitive science knowledge into survey research started in the 1980's was called the Cognitive Aspects of Survey Movement (CASM) and continues to this day. For a brief history on the topic, see the Preface of Tanur (1992).). An example is the classic question response model proposed by Tourangeau (1984), which involves question comprehension, memory retrieval, the judgment of the relevance of retrieved information, and the selection and editing of the final response (Tourangeau et al. 2000). Although the role of memory is important in the answering of any question, in the case of time studies as time diaries or calendars, the role of memory is crucial as respondents are queried about past events that they have experienced. For instance, the American Time Use Survey (ATUS), which is a time diary survey conducted by the US Census Bureau to understand the time-use patterns of the population of the United States, asks the following question: "Now I'd like to find out how you spent your time yesterday, from 4:00 in the morning until 4:00 AM this morning. I'll need to know where you were and who else was with you" (Phipps and Vernon 2009). Likewise, a great reliance on memory processes will occur with questions asked about longer periods of time, such as with the Panel Study of Income Dynamics, a prospective national study of life course socioeconomics and health, which asks the following question: "I'd like to know about all of the work for money that you have done since January 1, [Past year]. Please include self-employment and any other kind of work that you have done for pay." In both circumstances, respondents will need to retrieve information from their autobiographical memory. Importantly, if the past 24 h or the past year consisted of complex experiences by including several different activities or jobs, respondents will have to make a considerable memory effort to derive a complete and accurate answer.

Belli and colleagues have noted that calendar questionnaires encourage the use of cues that exist in the structure of autobiographical knowledge which, together with flexible interviewing, enhance the quality of retrospective reports in comparison to

conventional standardized questionnaires (Belli 1998; Belli et al. 2001b). Importantly, they have shown that improvements in retrospective reporting also occur when collecting subjective assessment information, such as health status over the life course (Belli et al. 2012). In particular, they have noted that events that are more easily remembered can become memory cues that will help respondents to remember events that are more difficult to remember (see Belli 2013). There are three possible types of cueing: top-down, sequential, and parallel cueing. Top-down cueing occurs when more general events serve as cues to remember more specific ones: remembering the name of an employer helps remembering more specific details such as weekly pay. Sequential cueing occurs when a remembered event is used as an anchor that aids in the remembering of a temporally adjacent event within the same life domain: remembering that one worked for one employer during a period of time helps remembering the name of the employer one worked with afterwards. Finally, with parallel cueing, a remembered event in one life domain assists in the remembering of an event from a different life domain that occurred contemporaneously or nearly so: remembering a change of residence helps remembering that one changed employment.

Time diaries also take advantage of these cueing properties, although differently. Whereas calendars encourage respondents to report about periods of stability and points of transitions in different life domains (work, relationships, health), time diaries ask about transitions between the different activities one engaged in during the day. In calendar surveys, respondents provide information about a number of timelines covering events from the different life domains of interest, and reference periods can range from months, to years, and up to the entire lifetime. In time diaries, respondents provide information about activity sequences, and the context in which these occurred; their reference period is generally 24 h. In terms of cuing, given that time diaries are driven by location, transitions between activities generally involve a change in location (within the house or traveling to a different place) (Stafford 2009). Hence, top-down cuing may occur in which the more general event (the activity) will trigger one to remember the more specific detail of “where.” A bottom-up cueing can also occur as one may first remember “where” before remembering the activity. Likewise, sequential cueing may occur regarding the details and context of the activity in which remembering one activity may assist in the remembering the next. Finally, parallel cueing may occur when a person reports a secondary contemporaneous activity.

Research has found that timeline methods (especially calendars) do enable more complete reconstructions of one’s past and an enhancement in retrospective reporting data quality (Belli et al. 2004, 2013; Bilgen and Belli 2010). Given that social, behavioral, and health scientists will continue to administer surveys that ask respondents about their pasts, such interviewing methods are encouraged in order to produce more valid scientific inferences about individual life course trajectories and social interrelationships (This section draws heavily on Belli 2013).

4 Applying Time Diary and Calendar Methods to the Analysis of Well-Being

An important feature of data collected through a time diary or a calendar is that they can be used not only to create simple individually aggregated summaries, but summaries that can give account of “complex constructions” (Stafford 2009). For instance, in the area of employment histories, calendars can be used to construct summary employment measures for the entire 52 weeks of the year (such as employment periods, sick periods, being on vacation, and being out of the labor force). In addition, complex constructions can be created for calendars by analyzing descriptors. For instance, by asking about hours worked in more than one job or about a second job at a lower wage rate, calendars can permit the descriptive characterizations of multiple job holding status over the course of a determined amount of time. Likewise, descriptors can be used to characterize a given spell or episode, as well as to track their sequence. For example, complex constructions can be captured regarding the type of employment spell, such as full-time or part-time, or whether one was unemployed or out of the labor force due to an injury. Descriptors can also tell us whether the weeks of unemployment during a calendar year correspond to one spell or a number of shorter spells, as well as their timing. These distinctions, which are critical for the correct analysis of labor economics, are not available from summary measures using noncalendar methods.

Similarly, the data obtained from individual 24-h time diaries can be processed into overall time-use measures with which to account for how a society as a whole allocates time into the different activities and how these are distributed across different subgroups (e.g., housework for males and females). Complex constructions can also be created through microdiary activity data, in which descriptors of the activity (where, who with, secondary activities) can be included. Such descriptors are critical to understanding the patterns of social interactions, such as child or elderly care. Similarly to calendars, the resulting complex timelines overcome the limitation of time-use aggregate measures which are not able to track the sequencing of activities. For instance, in a diary using stylized lists, one may know the total amount of hours of television watching or sleep, but their sequencing remains unknown. Finally, diary activity records are also amenable to the inclusion of subjective descriptors such as affect, whereby elapsed time can be characterized as productive, enjoyable, unpleasant, or meaningful. Including affect descriptors can be extremely useful in the assessment of well-being, even in spite of the fact that diaries only provide a small snapshot of the life of respondent (Stafford 2009).

In summary, time diaries and calendars are a valuable tool for the measurement and analysis of many aspects that impact well-being. Their capability of including descriptors reduces the potential for biases that can arise from respondents' direct reports of activities or spells over a “typical month,” a “typical week,” or a “typical day,” where averages and timing of events can be considerably imprecise due to socially desirable answers or the reliance on stereotypic responses (e.g., 40 h of work per week). The literature has shown several examples of how time diary and calendar methods can provide a theoretic framework for the analysis of well-being through the collection of valid and reliable information.

4.1 The Currency of Life: Measuring Well-Being Through the National Time Accounting Framework

Based on the ideas proposed by Juster et al. (1981, 1985), the pursuit for a new system of accounts that will allow the measurement of well-being in a more comprehensive fashion – one which would include how time is experienced – gained momentum. During the first decade of the twenty-first century, the idea of establishing a system of “National Time Accounting” (NTA) was presented by Krueger and colleagues (Krueger 2009a, b; Krueger et al. 2009a, b). This new system of accounts is dependent on self-reported data of subjective outcomes (“subjective well-being”) that is to be measured and reported *in tandem* with traditional national estimates of a country’s economic activity in order to measure overall well-being. The NTA is a “framework for measuring, comparing, and analyzing the way people spend their time across countries, over historical time, or between groups of people within a country at a given time” (Krueger 2009a, p. 2). It is based on time-use and its affective (emotional) experience. The novelty of this method is that time-use evaluation does not rely on researchers’ or coders’ judgments about whether an activity constituted enjoyable leisure or hard or tedious work or home production. The NTA approach, referred to as the “evaluated time-use” approach, relies on individuals’ own evaluations of their emotional experiences during their various uses of times. In it, respondents can express emotions in a multidimensional fashion: they can be happy, tired, and stressed, all at the same time, during a certain activity or situation.

Just as their predecessors from the mid-1980s, the proponents of the NTA base their theory on a critique to the National Income Accounts (NIA) system, as such measures (e.g., GDP per capita or consumption per capita) only represent a piece of total welfare. For them, well-being is more than economic output and material consumption. Notably, certain factors that may contribute to economic output (pollution due to increased production) may actually be detrimental to people’s well-being. In contrast, factors that contribute to well-being (socializing with friends) are not measured by national income. Similarly to Juster and colleagues, Krueger et al. (2009b) do not intend to substitute the NIA, but to complement it, recognizing that the NTA is still incomplete and only provides a partial measure of society’s well-being. Nonetheless, their evaluated time-use approach does provide an additional valuable indicator of society’s well-being. Moreover, the NTA can offer analytical and political advantages that may not be available from other type of measures of subjective well-being including those of overall life satisfaction.

The NTA framework is built on Juster’s concept of the “process benefits” of activities (Juster 1985), defined as the set of satisfactions that emerge from activities themselves. Juster, however, did not link the satisfaction evaluation to the specific activity reported, but to how individuals enjoyed the activity or situation *in general*. Such an approach failed to capture what people actually experienced and resulted in profound discrepancies between concurrent and retrospective reports of affective experience (Schwarz et al. 2009). Therefore, in the NTA framework, time diary methods are utilized in a way that respondents

connect specific events that actually occurred to the way they affectively experienced them. Four potential biases are prevented: (1) respondents do not need to develop a theory of how much they should be enjoying that activity in general in order to construct an answer to the question; (2) respondents will be less sensitive to the interviewers' opinion about them, as one is only talking about an specific instance (i.e., respondents will feel less self-conscious by reporting that one particular time they were not happy while taking care of their children); (3) respondents are not put in the position of needing to accurately aggregate their experiences over many times they engaged in a particular activity in order to provide a "general activity judgment"; and (4) the potential for selection bias will be less likely, as respondents will not need to choose from their past memories the best or worst moments of a particular type of activity in which they were engaged (Krueger et al. 2009b).

Finally, within the NTA approach, the uncertainty of whether individuals interpret enjoyment scales in an interpersonally comparable way is potentially better handled. The NTA framework proposes the U-index, where the U stands for "unpleasant" or "undesirable," with which the authors address the problem of comparability by focusing on measuring the proportion of time an individual spends in an unpleasant state. This approach allows for the computation of an average U-index for a group of individuals. According to its proponents, the virtues of this statistic are that it can be immediately understandable and serves as an ordinal measure *at the level of feelings*.

Two serious critiques have emerged toward the NTA's approach. First, the fact that reducing emotional experiences to a dichotomous characterization (pleasant or unpleasant) reduces the amount of information about the intensity of positive or negative emotions. The second critique is that the NTA only provides information about episodic feelings and cannot account for people's general sense of satisfaction with their lives as a whole. The best example for this is given by Loewenstein (2009) who argues that traveling to a new a different country is fraught with uncomfortable and unpleasant situations (e.g., airport long lines). However, the experiences gained from traveling may be extremely valuable and can make one a happier and wiser person. In spite of these criticisms, Krueger and his colleagues (2009a, b), along with numerous other prominent authors, have been able to provide empirical evidence that self-reported affect, even reduced to a binary scale, can predict important (objective) life outcomes, especially with regard to the quality of individuals' social life, work stability, longevity, and the quality of health. Significantly, in the areas of health psychology and behavioral medicine, it has been shown that positive and negative affect play a central role in health outcomes, particularly in connection with the translation of the psychosocial environment into physiological states. In sum, collecting emotional experiences directly connected to actual occurrences has proven to be useful in terms of predicting future crucial life outcomes, and thus, there is "signal" in people's self-reports of their affective experiences which is possible to be analyzed and interpreted.

4.2 Event History Calendar Methods to Assess Health-Related Issues

Calendars have the capacity to more fully capture concurrent activities or events, as they not only capture incidence of events, but also their timing and patterns (Stafford 2009; Barber et al. 2016). Indeed, calendars allow for the examination of timing and sequencing of events in different domains and thus provide a rich picture of potential causal mechanisms in the development of a person's well-being (Barber et al. 2016). Likewise, calendar interviewing methodology has been shown to produce high-quality retrospective reports. Such positive outcomes result from the ability of calendars to encourage respondents to reconstruct periods of social (e.g., residence, marriages), economic (e.g., employer names) or health-related (e.g., tobacco use) episodes of activity or statuses, by using chronological time and their previous own experiences memory cues (Belli et al. 2009b). Studies using calendars can include a variety of modalities, including face-to-face and telephone modes, paper-and-pencil and computer-assisted interviewing methods, and life course and shorter reference periods (Belli et al. 2001b, 2007; Yoshihama 2009).

Because of these advantageous properties, calendars have been applied to several areas of research related to the diverse components of well-being, such as education, employment, and, more recently, to the consequences of exposure to political violence (McNeely et al. 2015; Barber et al. 2016). Among the various components of well-being, using calendars to measure health conditions (e.g., women's sexual health, alcohol abuse, mental health, adolescent health, health status of the elderly) has been dominant.

One area of study using the calendar method is that related to adolescent health research (Martyn 2009; Luke et al. 2011; Martyn et al. 2013). This topic has garnered interest because of the high rates at which adolescents get involved in risky sexual behaviors. The 2013 CDC Youth Risk Behavior Surveillance Survey of US high school students showed that 47% engaged in intercourse, 15% had intercourse with four or more people, and 22.4% drank alcohol or used drugs before their last sexual intercourse (Centers for Disease Control and Prevention 2014). Ensuing problems include the increasing rates of STDs among the 15- to 19-year-old population as well as unwanted pregnancies (Martyn et al. 2013). In an effort to improve adolescent report and awareness of their sexual risk histories, and to improve the communication between adolescents and their health care providers, Martyn and colleagues (Martyn et al. 2006; Martyn 2009) developed a self-administered calendar to study this issue. In addition to the privacy benefit of the self-administered questionnaire, by which adolescents felt freer to report potentially sensitive information without concerns about being embarrassed, the studies were able to show that one of the main advantages of using a calendar was that it provided adolescents with the opportunity to not only record and view their behavior and life events over a 3-year period, but also reflect on the interrelationships between behaviors and events. According to Martyn and colleagues, the calendar not only allowed the collection of risk behaviors, but also fulfilled the

objective of achieving an increased risk perception and communication among the adolescents involved in the study. Importantly, such increased awareness is associated with the ability of calendars to visually show information that is contextually and temporally linked, encouraging adolescents to put their lives in context, and allowing them to see more clearly the consequences of their decisions across their different, though interrelated, life domains. Additionally, the self-administered calendar enabled a rich qualitative discussion about the reasons they engaged in risky behaviors, as well as their future behavioral intentions. What is more, Martyn et al. (2006) showed that adolescents reported decreased risk intentions and behaviors. Indeed, in a 3-month follow-up survey, adolescents reported increased abstinence from sexual activity and of the use of tobacco, alcohol, or marihuana (Martyn 2009). Calendars were shown to be a powerful tool to not only analyze current adolescent health risk behavior and predict future developments, but to also devise possible intervention research studies that can have an impact on adolescent's future health and well-being.

The second example of the use of calendars related to health and well-being is the Pitt County Study in North Carolina, an investigation of social, economic, and behavioral precursors of cardiovascular disease in Southern African Americans. The objective of the study was to link information on childhood socioeconomic condition, obtained retrospectively, to health outcomes in African American adults (Belli et al. 2009a). Importantly, this was the first time in which a calendar was used to measure economic and psychosocial factors relevant to life course social epidemiology research. The calendar instrument that was utilized included eight conceptual life domains, designed to collect periods of stability and transitions between these periods for the entire life course. Smoking was the domain corresponding to the health behavior of interest. The other domains tried to capture key dimensions of social and economic well-being and included the following: household utilities, the family's exposure to economic hardship, social and material life conditions, organizational memberships, relationships with parents/guardians during the respondent's childhood, relationships with other family members, and the individual's exposure to unfair treatment (Belli et al. 2009a).

In the Pitt County study, the calendar was able to produce retrospective data of reasonably high quality, as was expected from an instrument designed to optimize the accuracy of autobiographical recall. Additionally, it was found that the calendar also contributed valuable data to other studies with original research questions within a population with many preventable risk factors for chronic diseases (See, for instance, James et al. 2006). Finally, the average administration time was of 30 min, which was confirmation of the practicality of this instrument for the use in large-scale, community-based health research. The Pitt County study was innovative by implementing a computerized calendar. Design improvements are still possible, especially to overcome the disadvantage that computerized instruments cannot be readily shared with respondents for them to view the calendar elements together with the interviewer. However, in spite of such challenges, it was

demonstrated that it is feasible and useful to utilize computerized calendar elements to conduct life course epidemiological research, as the retrospective data produced by the calendar method were able to expose important associations among early life socioeconomic conditions and later life risks damaging to well-being such as obesity, hypertension, and cigarette smoking.

5 Conclusion and Future Directions

The predominant economic tradition has tended to equate an increase in national income statistics with an increase in well-being. This perspective can be misleading as it does not acknowledge that well-being is much more than material welfare and is shaped by a multidimensional set of factors. Notably, what ultimately matters when it comes to “quality of life” are not objective wealth conditions, but rather the degree of enjoyment of engaging in activities associated with production and consumption (Juster 1985; Gershuny and Halpin 1996). This realization paved the way to the introduction of a new paradigm to assess well-being, one which involves the analysis of how time is experienced in people’s lives.

Such analyses necessarily involve methods that can reliably capture complex interrelations and dynamics, as well as subjective perceptions of personal and societal well-being. Empirical research has demonstrated advantages of calendar and time diary methods in the collection of well-being data. In contrast to conventional standardized questionnaires, time diaries and calendars place activities in context. In consequence, a broad range of subjective and contextual data can be collected through these methods (e.g., where, who with, perceived satisfaction, level of stress, and so on), with the advantage that respondents and interviewers can use their own words and repair misunderstandings as afforded by a flexible approach to interviewing. Moreover, such additional contextual details are not only important because of the extra information they provide, but because they contribute to enhance the quality of the data collected. In effect, Belli and colleagues (2009b) have concluded that compared to standardized interviewing methods, the temporal cues that emanate from calendar and time diary interviews assist respondents in providing retrospective reports more completely and accurately, even when these are of a subjective nature (Belli et al. 2012).

The use of time diaries and calendars to assess well-being is an emerging method that can be further developed. Comparable information on well-being across time and countries collected using these methods is still lacking. Efforts from international bodies such as the Better Life Index from Organization for Economic Co-operation and Development (OECD) are noteworthy in that they wish to incorporate more dimensions to well-being besides material welfare. However, they are still based on averages and not on reliably and validly measured indicators of subjective satisfaction with the various domains of life, indicators that may capture the “final output” of what makes life worthwhile.

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Body Mapping in Research

70

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Contents

1	Definition of Body Mapping	1238
2	The Process of Body Mapping	1239
3	History of Body Mapping	1240
4	When Is Body Mapping Used?	1240
5	The Varied Uses of Body Mapping	1241
6	Examples of Body Mapping Studies	1241
7	Things to Consider When Planning a Study Using Body Mapping	1243
7.1	Will Body Mapping Facilitate Answering the Research Question?	1243
7.2	Has the Purpose of the Body Map Been Made Clear in the Study?	1244
7.3	Is Body Mapping an Appropriate Technique to Use with the Participants?	1244
7.4	What Other Qualitative Methods will Be Used in Conjunction with Body Mapping?	1244
7.5	How Many Contact Sessions will Be Required with Participants?	1245
7.6	How Structured will the Body Mapping Sessions Be?	1245
7.7	How and What Data will Be Analyzed?	1245
7.8	How to Conduct a Body Mapping Study	1246
8	An Example of a Study Using Body Mapping	1246
8.1	Subjective Experiences of Depression	1249
8.2	Idioms of Distress Used by Adolescents Living with HIV	1249
9	Methodological Rigor	1251
10	Ethical Aspects of Body Mapping	1251
11	Conclusion and Future Directions	1253
	References	1253

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Abstract

This chapter describes the methodology of body mapping, a visual technique that is used to collect qualitative data from participants about their subjective experiences pertaining mainly to bodily experiences. We begin with a definition of body mapping and provide an account of its history. We describe the process of conducting a body mapping study and offer some examples of when this approach is used most appropriately in its various forms. In preparing to use a body mapping approach, researchers should be mindful of whether body mapping is the best approach to answer the research question; whether the purpose of the body map been made clear in the study; whether it is an appropriate technique to use with participants; what other qualitative methods will be used in conjunction with body mapping; how many contact sessions will be required with participants; how structured the body mapping sessions will be; and how the data will be analyzed. We provide a detailed example of how to conduct a body mapping study and call attention to important considerations such as ensuring methodological rigor and the ethical aspects of using this approach. Body mapping is an innovative methodological technique that is often able to capture the imagination of research participants. Our aim in this chapter is to convince readers that body mapping has its place as a methodological approach alongside a range of other approaches in social and behavioral research.

Keywords

Body mapping · Research · Methods · Qualitative · Visual methodology · Social science

1 Definition of Body Mapping

Body maps or body-mapping, as it is commonly referred to in the literature, is both a therapeutic technique and research tool that prioritizes the body as a way of exploring knowledge and understanding experience. Life-size body drawings are either drawn or painted to visually depict aspects of people's lives, their bodies, and the world they inhabit (Gastaldo et al. 2012). These life-size artworks have been likened to totems (sacred objects or symbols) as they often contain symbolic value. The meaning of a body map may be fully understood only by the accompanying story and experience of its creator.

Researchers in the human and social sciences often refer to body mapping in research as body-map storytelling. Body mapping is considered as “a data generating research method used to tell a story that visually reflects social, political and economic processes, as well as individuals’ embodied experiences and meanings attributed to their life circumstances that shape who they have become” (Gastaldo et al. 2012, p.10). Body mapping is a visceral approach to data collection and elicits data pertaining to the emotions of the body (Sweet and Escalante 2015).

Sweet and Escalante (2015) have identified three broad elements that constitute a body mapping approach, namely, (1) the life sized body map, (2) the *testimonio*, and (3) the key. The body map is a pictorial outline of the participant's body and is therefore a visual representation of his or her physical form. The *testimonio* is a short story narrated by the participant that is activated by the body map and that pertains to the research question at hand. The narrative is recounted in the first person and is a detailed description of each visual element that is documented on the body map.

Body mapping falls under the umbrella of participatory qualitative research (see also ► Chap. 17, “Community-Based Participatory Action Research”). It is often used to complement traditional qualitative data collection techniques such as interviews and focus groups. The approach is rooted in a therapeutic process known as narrative therapy (Santen 2014). Narrative therapy seeks to conceptualize psychological problems as distinct from the individual person and assumes that patients have many skills, areas of competency, assumptions, values, beliefs, and abilities that may be harnessed to help them ameliorate the impact their problems have on their lives (Morgan 2000). The combination of body maps and narrative therapy gives rise to a creative therapeutic technique that allows for the expression of individual experience through visual art.

2 The Process of Body Mapping

Participants who are recruited into a study involving the technique of body mapping assume a horizontal lying position on a large sheet of paper which is placed on the floor. A second person, the researcher, an assistant, or co-participant, draws an outline of the person's body on the sheet of paper (see Fig. 1). The participant is then asked to examine the outline, which serves as a springboard for discussion in

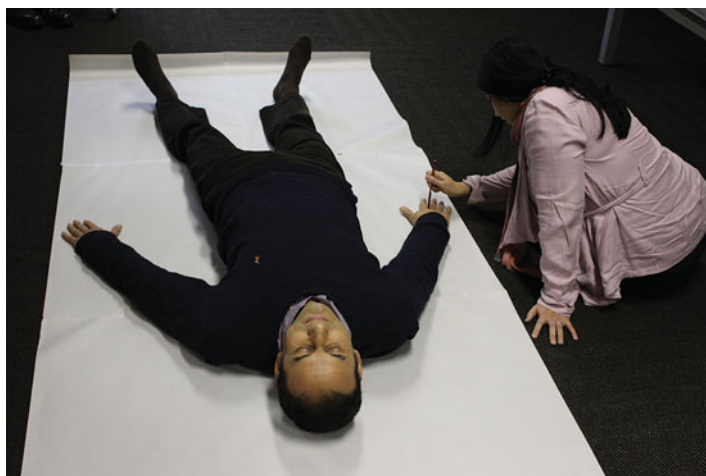


Fig. 1 Body mapping example showing the activity of tracing outlines of the participant's body on large sheets of paper

the research interview. The researcher poses questions based on the outline, to which the participant responds by using colors, symbols, or words to represent their answers and thus also, their experiences. The evolving artwork provides a means for the individual to externalize somatic and emotional experiences in a way that is appropriate and understandable to them (Solomon 2002). The body map thus facilitates an interactional interviewing style where visual cues become the basis for probing (Cornwall 2002).

3 History of Body Mapping

In the early 1990s, Andrea Cornwall, an anthropologist from London, used body mapping with Zimbabwean women as a way to access local knowledge of reproductive health and contraception. In the context of ambiguity in language and the importance of indigenous knowledge when attempting to understand illness, Cornwall and her colleagues showed that body maps were useful ways to understand the terminology used and perceptions held by the participants regarding their bodily processes.

In South Africa in the early 2000s, body mapping was used among women living with HIV (Braque 2008; MacGregor 2009). A clinical psychologist, Jonathan Morgan, in collaboration with the AIDS and Society Research Unit at the University of Cape Town, used the technique as part of the Memory Box Project, which was a community outreach program organized through the AIDS and Society Research Unit (Morgan 2003). Rather than artistically drawn bodies, memory boxes (i.e., boxes made out of cardboard and other recycled materials) were used by the research participants to visually depict their stories. The first series of memory boxes were put on display at the 2000 Durban AIDS conference. Soon after and following the success of using visual methodologies to depict experiences, Jane Solomon, a South African artist, developed a guide for body mapping and used it as an advocacy tool to call attention to the magnitude of the HIV/AIDS pandemic in Africa.

4 When Is Body Mapping Used?

Body mapping is known for its use as a therapeutic tool, especially among individuals living with HIV (Solomon 2002). Increasingly, body mapping has been used as a research method and has been applied creatively and constructively across various academic disciplines (Brett-MacLean 2009; MacGregor 2009; Gastaldo et al. 2012; Griffin 2014). For example, in Canada, Crawford (2010) used body mapping as a therapeutic tool for people with alexithymia or somatic issues following a trauma. Also in Canada, Denise Gastaldo et al. (2012) used body mapping as a research tool to document health problems and migration experiences of undocumented laborers in Toronto. In both studies, body mapping was an appropriate method as it provided a platform for participants to engage with researchers, which may otherwise have been challenging if only interviews had been used.

Body mapping as a methodological approach to facilitate the collection of qualitative data is often appropriate among children and adolescents who are not yet able to coherently express their experiences with language alone. With the use of this method, children are able to respond creatively to interview questions on a full size paper outline of themselves.

5 The Varied Uses of Body Mapping

Body mapping, as described by Solomon (2002), may be used as a treatment information and support tool, as an advocacy tool, an intergenerational dialogue tool, a team building tool, an art making tool, and a biographical tool.

As a treatment information and support tool, body maps can be used in workshops to educate individuals about a particular treatment regimen. For example, healthcare workers or adherence counselors can use body maps with individuals enrolling on antiretroviral therapy (ART). The body maps may be used to illustrate how ART strengthens immune systems and to create awareness of its potential side effects.

As an advocacy tool, body maps can be displayed at exhibitions or published in books or online with the purpose of creating awareness of various personal, social, economic, health, or political issues, for example, the effect of pollution on health. These displays become a platform on which activists communicate their feelings, thoughts, and ideas about these issues.

As an inter-generational dialogue tool, body maps bridge intergenerational gaps. They can therefore be used as a means for young children to communicate with their parents or caregivers and to establish trust and deepen emotional connections.

As a team building tool, body maps can be used to establish trust and form relationships between people. It can be used to highlight the importance of embracing differences and working together towards a mutual goal.

As an art making tool, body maps can be used to facilitate art classes. As a form of art, the technique is also likely to foster creativity among research participants, thus potentially yielding rich data.

As a biographical tool, body maps can be used to construct biographies (personal narratives about life histories).

6 Examples of Body Mapping Studies

Most research utilizing body mapping has been conducted in the fields of HIV, trauma, and violence, but researchers have also used body mapping to investigate issues such as wellbeing, pain, and risky behavior. As mentioned previously, body mapping is typically used in conjunction with other qualitative methods such as interviews and focus groups in research. Table 1 contains a summary of nine studies that have used body mapping as a methodological tool. The table is not an exhaustive list, but is presented as an example to illustrate the broad range of topics, samples, and methodology that have used body mapping.

Table 1 Summary of studies that have employed body mapping as a method

Study	Year	Aim	Methods	Notes
Brett-Maclean	2009	To explore identity in PLWA	BM workshops conducted with 3 HIV-positive men in South Africa	Results published as an exhibition
Crivello, Camfield and Woodhead	2009	To determine suitable methods to explore well-being among children	Study reports on three qualitative methods used in project (BM, life-course timeline, group discussion)	BM provided visual stimulus
Joarder, Cooper, and zaman	2014	To explore meaning and perceptions of death of elderly people in a Bangladeshi village	BM used in conjunction with individual interviews, informal discussions and recording of daily routines BM was used to generate narratives Only narratives were analyzed	
MacGregor	2009	To trace personal and political dimensions of HIV/AIDS in South Africa	BM workshops conducted by peer counselors Participants reflected on BMs	Data analysis was not clearly outlined
Maina, Sutankayo, Chorney and Caine	2014	To understand how	BM workshops conducted with nursing students Data collected using individual interviews in which three participants reflected on BM Interviews were transcribed and thematically analyzed	BM was used as an intervention tool and no data related to the BM exercises were analyzed
Apiyo	2012	To explore personal stories of violence	BM workshops conducted with women who experienced violence Narratives elicited from BMs were reported	
Senior, Helmer, Chenhall and Burbank	2014	To explore young people's perceptions of risk from STIs in rural Australia	BM workshops conducted with participants Data collected via interviews, group discussions, and BM	No guidelines on analysis

(continued)

Table 1 (continued)

Study	Year	Aim	Methods	Notes
Silva-Segovia	2016	To explore self-perception of an imprisoned woman in Chile	Case study design with one participant BM was one of a number of methods used Study also relied on intertextual analysis, autobiographical fragments, self-interpretation, and reinterpretation of pictures	No guidelines to analysis and integration of analysis
Tarr and Thomas	2011	To explore body mapping as a method for representing pain and injury	Mixed methods: Questionnaires, interviews, BM 205 dancers	No details on analysis

7 Things to Consider When Planning a Study Using Body Mapping

While the above studies provide good examples of body mapping research, there are a number of questions to consider in planning such a study. Some questions are provided below:

7.1 Will Body Mapping Facilitate Answering the Research Question?

The most important consideration when selecting any methodological approach is the research question. Thus, the way the research question is asked will inform the method that is selected. Body mapping is, therefore, only useful if it is appropriately matched to the research question. The approach typically lends itself to qualitative research in which the task at hand is to generate a thick description of research participants' experiences. In our experience, typical research questions with which body mapping may be used often pertain to somatic concerns, stress and trauma, and health and illness. Thus, body mapping is well suited to the fields of health psychology, behavioral medicine, and medical anthropology. Using the body map as a springboard for the interview conversation, the interviewer can create a rich narrative that reflects the participant's subjective experience of the research topic of interest.

7.2 Has the Purpose of the Body Map Been Made Clear in the Study?

Body maps can be used for a number of purposes such as providing participants with a means of expressing their thoughts and feelings, as an intervention or educational tool, or as a stimulus. The reason for using body mapping in research needs to be made explicit to the participant. For example, it can be explained that the body map is intended to elicit a rich narrative from participants about their experiences and the meaning they create from these experiences. It can also be explained to the participant that the body map is the main tool of data collection and provides the data that will then be analyzed.

7.3 Is Body Mapping an Appropriate Technique to Use with the Participants?

Body mapping is especially appropriate when participants have difficulty expressing themselves verbally. The visual experience of appraising one's self-constructed body map provides a useful platform for verbal expression and elaboration. For example, Crivello et al. (2009) used body mapping to explore subjective well-being among children. In their study, body maps provided a useful starting point for discussions with children. The researchers stated that body mapping was a more appropriate technique than individual interviews as children found the novelty and creativity of body mapping to be more appealing than interviews on their own. The similarity and overlap of body mapping with play made the approach especially suited to the research question and the population of interest, i.e., children.

7.4 What Other Qualitative Methods will Be Used in Conjunction with Body Mapping?

One of the key components of qualitative research is to establish credibility and trustworthiness of the research findings. Using more than one qualitative method creates opportunities for such rigor to be applied, for example, by supplementing body maps with in-depth or semi-structured interviews or focus groups. Joarder et al. (2014) used body mapping in combination with in-depth individual interviews, informal discussions, and recording of daily routines in exploring a sample of elderly participants' perceptions of the meaning of death. Similarly, Silva-Segovia (2016) used body mapping, intertextual analysis, autobiographical fragments, self-interpretation, and reinterpretation of pictures in analyzing the case study of an imprisoned woman in Chile. These examples illustrate that a range of qualitative techniques can be useful in combination with body mapping. Tarr and Thomas (2011) combined qualitative and quantitative methods in their explorations of pain and injury among dancers in the United Kingdom. In their study, body mapping and interviews were used in conjunction with questionnaires to answer the research questions pertaining to pain and injury as a consequence of dance.

7.5 How Many Contact Sessions will Be Required with Participants?

It is necessary to decide on the number and length of the body mapping sessions and other forms of data collection. This decision is usually based on a number of factors, including the purpose of using body mapping, the characteristics of the participants, and the nature of the research question. If body mapping is used as part of an intervention or as part of an in-depth case study, the researchers may consider a series of body mapping workshops. For example, researchers using body mapping as a means of stimulating discussion may use one workshop, followed up by an interview or series of interviews. Main et al. (2014) used body mapping as an educational tool and conducted one 4-h long workshop with participants. Participants completed the body maps in groups of three to five participants, after which the researchers conducted in-depth interviews with each participant. There is no specific formula for making these decisions. The approach is fairly flexible and responsive to the research question at hand.

7.6 How Structured will the Body Mapping Sessions Be?

The structure of body mapping sessions can be designed to answer the research question. We suggest a semi-structured approach in which the content of the interview is guided by an interview schedule that uses open questions, probes, facilitative statements, paraphrasing, and reflection. The body map is therefore a springboard to the interview conversation and is intended to generate speech from the participant that forms the qualitative data that will then be analyzed.

7.7 How and What Data will Be Analyzed?

It is important for the researcher to consider whether to only analyze the body map, the accompanying narrative, or to include both forms of data in the analysis. One shortcoming of many existing body mapping studies is that researchers often failed to report how they analyzed the data. This omission was evident in a number of studies listed in Table 1 (MacGregor 2009; Tarr and Thomas 2011; Senior et al. 2014). In several studies, body mapping was used as a technique to elicit a narrative from participants, which was recorded, transcribed, and coded for analysis. For example, Apiyo (2012) conducted body mapping workshops with women who reported experiencing violence. The body maps themselves were not analyzed but instead used as a tool to elicit narratives from participants. Maina et al. (2014) used body mapping as an intervention tool with nursing students who were infected with HIV and taught others about the disease. In their study, the nursing students participated in a body mapping workshop that aimed to educate them about the social and personal aspects of HIV. The nurses were interviewed after the workshop and the interviews were transcribed and analyzed. The interviews were, therefore, the data collection tool, not the body mapping.

7.8 How to Conduct a Body Mapping Study

In Fig. 2, we describe seven steps to be taken when using body-mapping as a research method. These steps are: deciding on the research question, identifying the participants, developing the research protocol, collecting the data, practicing interview techniques, conducting the interviews, and recording and analyzing the data.

8 An Example of a Study Using Body Mapping

In this section, we provide an in-depth example of a study in which body mapping was used in an investigation of depression among adolescents in Zimbabwe. The study we describe was conducted among adolescents living with HIV in Zimbabwe, a group among whom depression has been found to be a serious mental health concern (Patel et al. 2007; Mellins and Malee 2013). In the context of limited research on the experience, impact, and manifestations of depression among Zimbabwean adolescents with HIV, one of the authors of this chapter, Nicola Willis, conducted a study using body mapping as a methodological technique. She sought to document the subjective experiences of depression among the adolescent participants, to identify the idioms of distress used by the participants, and to understand how the participants perceived their experiences as being addressed by families, communities, and service providers.

Nicola recruited 21 adolescents living with HIV who had a diagnosis of major depression from a community health program for children and adolescents living with HIV in Zimbabwe. The program provides community-based psychosocial support and health services to over 5,000 children and adolescents living with HIV in Zimbabwe (Jackson et al. 2015).

Body mapping was well suited to the adolescent population as this life stage is associated with significant physical and neurodevelopmental changes. In early adolescence, abstract and metaphorical cognitive abilities are still developing (Sawyer et al. 2012). Adolescents may be able to express themselves through body maps but may not be as able to reflect on or describe the meaning of what they have expressed. To this extent, body mapping methodology was well suited to investigate their subjective experiences and perceptions of the care they received at the community program.

Nicola sought to engage young HIV-positive research participants with depression in an exploratory process that would enable them to describe their experiences of depression and the ways in which they perceived care. She therefore selected a participatory, qualitative approach that drew on narrative therapy with body mapping as the methodological tool for data collection.

Narrative therapy is a therapeutic process that encourages the storyteller to regain a sense of authorship and re-authorship of their own experiences in the telling and retelling of their own story (White and Epston 1990) and to see their experiences as subjective and personal phenomena rather than as others perceive them. In narrative therapy, storytelling provides the opportunity for an exploration of the participant's experiences and provides in-depth insight into the ways in which participants interpret and understand their world. Narrative enquiry has been described as an effective

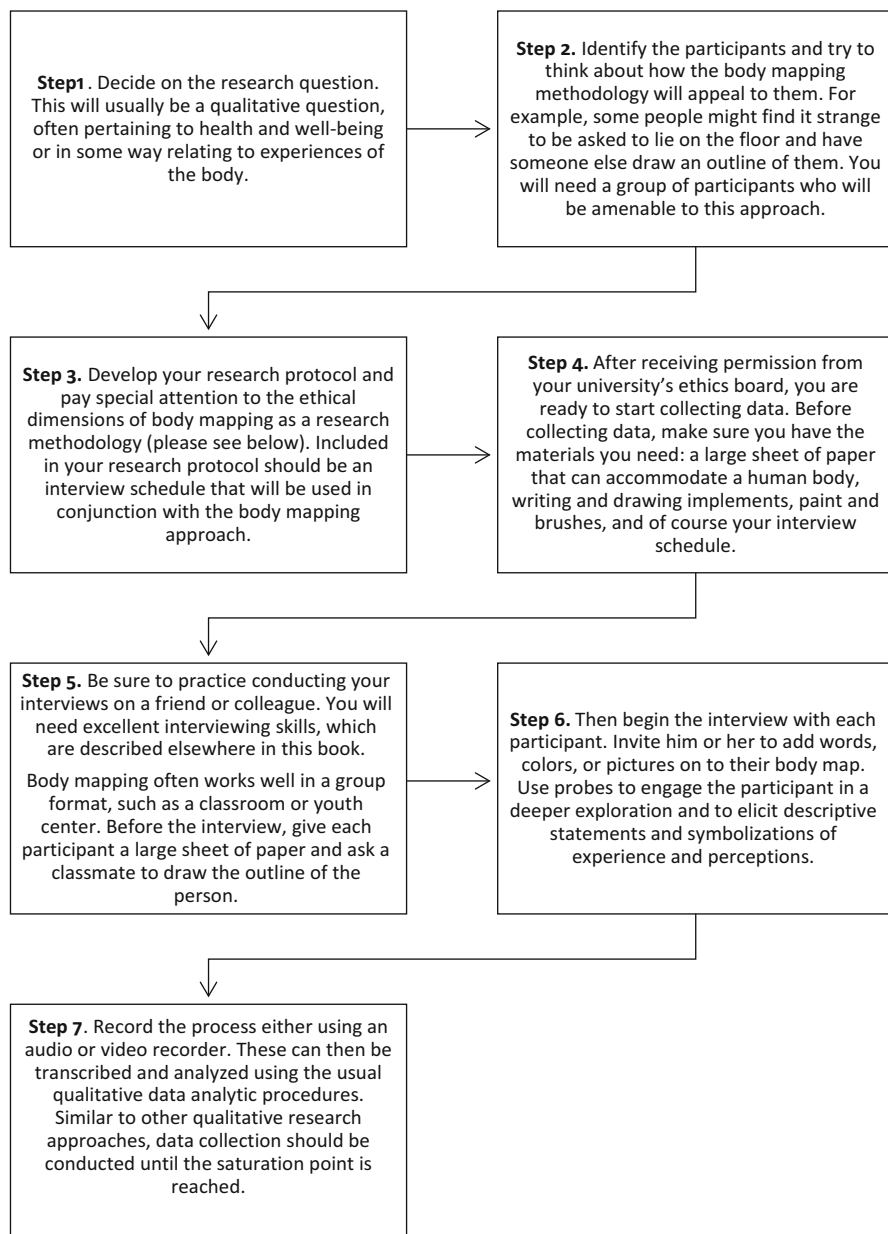


Fig. 2 Flow chart representing possible steps for undertaking research using body-mapping as a method

means to understand the complexities of the individual experience of health and illness. It has also been suggested that storytelling offers considerable value where the human experience of illness is unknown or unexplored (Greenhalgh 2001).

Nicola developed an in-depth interview schedule that was centered on the body mapping process. She used a semi-structured interview and body mapping guide (see below) to facilitate the interview so that she could engage participants in a creative dialogue around the research questions. The interview contained open-ended questions aimed at exploring participants' subjective experiences and perceptions of care. At the beginning of the process, she asked each participant to lie down on a large sheet of paper so that an outline of him or her could be drawn. She invited the participant to add words, colors, or pictures on to their body map and to assist them in responding to the questions. Nicola used probes to engage participants in an in-depth exploration of their experiences and to elicit descriptive statements and symbols of these experiences and perceptions. She developed the interview guide in consultation with one of her supervisors, a psychiatrist based in Zimbabwe, and counselors from the community program who had experience in body mapping.

As the interviews were based on the body mapping session, two types of data were generated, namely, audio data from the interview and visual data from the body map. Each interview was audio-recorded with the participant's consent. At the end of the interview, a photograph was taken of the body map. Two research assistants assisted with data collection throughout the study period. They were present during each interview to assist with field notes and practical issues associated with the body mapping itself, such as preparation of paints and water.

Each in-depth interview was transcribed and translated from Shona into English and the body maps were photographed. The transcripts were separately coded by two coders and the two sets of codes were compared and discrepancies resolved by discussion. Once the coding was consistent for both the transcripts, they were single-coded. Codes were then grouped into categories and emerging themes were identified following the general principles of thematic analysis (Attride-Stirling 2001; Braun and Clark 2006; see also ► Chap. 48, "Thematic Analysis").

The photographs of each body map were also analyzed along with the transcriptions. Common themes from the different interviews and body maps were then identified and were illustrated with quotes and images. Computer-assisted qualitative data analysis software (CAQDAS) programs, such as ATLAS.ti, are capable of managing several media including word and pdf documents, photo images, and audio files in nearly every available format. This software allows its user access to multiple media to formulate a meaningful interpretation of the data (Scientific Software Development 2003). In body mapping studies such as the one we describe, images from the body maps can be hyperlinked with quotations from the transcribed interviews. Codes emerging from the analysis and hyperlinked data can then be grouped together to reflect salient themes. The results of the study were organized in terms of the research questions, namely, to document the subjective experiences of depression among participants, to identify cultural idioms of distress, and to understand how depressed adolescents perceived their experiences as being addressed by families, communities, and service providers.

8.1 Subjective Experiences of Depression

Participants in the study described their lives as characterized by negative and traumatic experiences. They conveyed these descriptions through both their verbal narratives and the evocative imagery which they chose to paint on their body maps to illustrate their experiences and emotions. Seven main themes emerged from the data: (1) being different from others, (2) learning of their HIV status, (3) isolation and rejection, (4) loss and grief, (5) low self-worth, (6) lack of protection, and (7) the future. In addition, idioms of distress also emerged from the data.

8.2 Idioms of Distress Used by Adolescents Living with HIV

Thinking too much. Participants' idioms of distress were conveyed through both their verbal narratives and the words and images which they chose to paint on their body maps. The most commonly used term to describe depression was "thinking too much" or being "lost in thought" as a result of the events in their lives. Participants often chose to use a color they identified with depression such as black or red (see in Fig. 3 the painted parts of the body that they associated depression). The brain and heart were the parts of the body which they most commonly identified. One female participant used the color purple to link the different parts of her body affected by depression. She began by painting her head and her heart purple, explaining that these were the areas of the body that she associated with depression. However, she then painted her legs the same color, explaining that when she felt depression in her heart and head, it led her to wanting to walk to the dam to drown herself.

Stress. The next most commonly used term was "stress," which was represented by a specific color which participants chose and located on certain parts of their bodies. Participants tended to use black or red and painted this on the head of the drawn figure. Stress was often used in connection with "thinking a lot." One female participant explained that stress arises from deep thinking and in turn resulted in suicidal ideation.

Pain. Many participants referred to depression as the "pain" they experienced in their lives in relation to many of the themes reported above, including being different from others, their HIV status, their experiences of isolation, rejection, loss and grief, their feeling of being unprotected, and uncertainty for the future (see Fig. 3).

Darkness. Darkness was referred to widely when participants were describing their depression. It was illustrated by the use of color, with black being the most commonly used. They chose to paint specific places on the body with which they identified this darkness.

Suicidal ideation. Suicidal ideation was also described by several participants. Four participants named or painted the methods they considered to end their lives in the past, including poisoning, hanging, and drowning. In general, idioms of distress were identified and expressed through a combination of color, pictures, and words.

Perceptions of care. Participants identified four sources of care, namely, families, peers, and support groups, clinic staff. It was implicit in their narratives that psychosocial care could also help to prevent these difficult experiences and

Fig. 3 An 18-year-old female adolescent's body map depicting the words, "pain" and "suffer"



emotions. One female participant expressed her need for care and reliance on others for support by painting a stone in her heart which she colored brown.

Many participants referred to the care and support they had received from other young people living with HIV in the program. They illustrated these experiences by painting pictures of their friends and sharing the way peers had helped them to accept their HIV status and reduce their experiences of stress, isolation, and lack of hope for the future.

Participants frequently referred to the program's training and support center as a key source of care in their lives where they have found love and support. The program was often painted on to their maps and described as a place where young people were valued, loved, and supported.

At the end of each interview, participants were asked how they felt about having participated in the body mapping process and interview. All participants stated that they felt positively about the process, that they had found it helpful, and that it had helped them to share experiences and emotions which they had not previously done. They stated that they were able to express themselves and open up by drawing and writing what they had previously kept to themselves. Participants indicated that they recognized that this approach would help others to understand them better as it had enabled them to articulate thoughts and feelings which they had been unable to express to counsellors before.

The example above illustrates how body mapping may be used as a research tool to access thoughts and feelings related to their physical health.

9 Methodological Rigor

As body mapping is a method used to collect qualitative data, it is necessary to ensure trustworthiness of body mapping studies. Trustworthiness is central to qualitative research and researchers using body mapping are expected build trustworthiness into different aspects of their research design. According to Lincoln and Guba (1985), trustworthiness comprises four components namely credibility, transferability, dependability, and confirmability. Creswell (2014) has outlined eight procedures that can be used within qualitative research to improve trustworthiness. These procedures include prolonged engagement, triangulation, peer review and debriefing, negative case analysis, clarification of researcher bias, member checking, development of a rich, thick description, and external audit. (For a more detailed description, please see Liamputtong, 2013; Creswell 2014; see also ► [Chap. 63, “Mind Maps in Qualitative Research”](#)).

In our assessment of studies that used body mapping as a research method, we noted that studies reported their methodological approaches inconsistently. For example, many studies did not explicitly state the purpose of using body mapping or did not provide sufficient detail of the body mapping process. More importantly, studies failed to name the methods used in analyzing the data and did not describe the process of analysis. The lack of detail regarding the rationale for using body mapping, the implementation of body mapping exercises, and the analysis of body mapping data may be viewed as threats to the trustworthiness of studies. As with all qualitative research, trustworthiness should be built into every phase of the research process, i.e., from conceptualization of a study to the reporting of results.

While no techniques for enhancing trustworthiness have been outlined specifically for body mapping, we make the following suggestions for increasing trustworthiness when conducting body mapping research. These techniques are not unique to body mapping but can also be found in other forms of visual methodologies and qualitative research in general. We have adapted Creswell’s (2014) procedures to recommend the following (Table 2):

10 Ethical Aspects of Body Mapping

It is very important when explaining the body mapping technique to participants that they understand that they will be asked to lie down on the floor and that someone will outline their body using a pen marker. For some people, this will sound quite strange so the researcher might want to show them a picture of someone lying the ground and participating in such an exercise.

Similar to other research, informed consent is very important (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). This includes informed consent to participate in the research, to lie on the ground and for one’s outline to

Table 2 Establishing rigor and trustworthiness in body mapping data

Recommendation	Example
Conduct member checks (credibility)	Discuss the results of your analysis with participants to see if they approve
Peer debriefing (credibility)	Discuss your study and specifically your findings with peers to see if they agree with your analysis
Triangulation (credibility)	Use other forms of data collection such as focus groups or interviews
Persistent observation (credibility)	Aim for prolonged interaction with participants
Admit lack of generalizability	Acknowledge that findings from the research may not be generalized, but can be transferable
Describe the process of data collection	Describe the process of body mapping <ol style="list-style-type: none"> 1. Who conducted the exercise 2. How many people attended 3. Over how many sessions were the exercises conducted 4. Describe instructions given to participants 5. Describe interactions between data collector and participants
Describe the process of data analysis – Are the maps being analyzed or the narrative or both?	Describe which data are being analyzed, i.e., the body map, the narrative, or both If the body map was analyzed, describe the analysis process If the narrative was analyzed, describe the data analysis method used
Maintain an audit trail	Note all processes and attempt to verify as many aspects of the methodology as possible
Reflexivity	Practice reflexivity throughout the process

be drawn, to be interviewed, to be audio or video-recorded, and to have their body map photographed.

It is also necessary to obtain consent to use the data for specific purposes and to be specific about how data will be displayed. For example, participants need to consent to researchers displaying photos of the body maps either in journals or in exhibitions, even if their identity is disguised. Body maps cannot be exhibited unless researchers obtain explicit permission to exhibit the map.

Similar to any research, participating in body mapping research can cause participants to become distressed if their emotions are evoked during the process of data collection. It is important that the researcher puts in place a referral trajectory so that distressed persons can access psychological help if needed.

When referring to participants in the research report, the researcher should disguise their identities, for example, by using pseudonyms and removing any personal identifiers from the transcripts before these are analyzed.

Data labeled with an ID unique to that individual should be kept securely and separately from the interview transcriptions, audio data, and body maps. Names,

addresses, and locator information should be kept securely for follow-up purposes in a lockable filing cabinet, accessed only by the research team.

11 Conclusion and Future Directions

Body mapping is an innovative methodological technique that is often able to capture the imagination of research participants. For many participants, it can seem playful and fun, thus making the process of participating in a research study a pleasant one. The process of having the participant lie down on a sheet of paper and having their outline drawn can also facilitate a warm and engaging professional relationship between the researcher and the interviewer. Such a relationship can be extremely helpful in eliciting useful data that may inform the findings of the research. We believe that body mapping has its place as a methodological approach alongside a range of others in social and behavioral research.

Body mapping can be of relevance when conducting cross-cultural studies and can bridge language barriers between researchers and participants. This chapter has demonstrated the usefulness of body mapping, especially when engaging children and adolescents in research. Body mapping is a relatively recent methodological innovation that remains underutilized in both therapeutic and research settings. Visual-based methods provide attractive ways to communicate human experiences to the public. We encourage researchers and therapists to consider body mapping as a creative, interactive technique when working with participants and patients.

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Self-portraits and Maps as a Window on Participants' Worlds

71

Anna Bagnoli

Contents

1	Introduction	1256
2	Self-Portraits	1258
3	Maps	1262
4	Conclusions and Future Directions	1265
	References	1266

Abstract

Visual and arts-based methods can be extremely beneficial to research investigating people's lives, subjectivities, and identities. Well suited to a participatory style of research, these methods work as an excellent support to an open style of interviewing and can help seeing the world from participants' own perspective, thus providing an insight into their own interpretation of their worlds. This chapter will review the use of two visual methods that I applied in the context of interviews in different research projects: a self-portrait with which I asked for a self-presentation narrative, and a map with which I encouraged participants to reflect on significant relationships in their lives. The use of visual methods as a support to interviewing can facilitate participants to think laterally and be more creative in their answers, and also enable them to take the lead in the interview and establish their own priorities. Simple drawing tasks and other creative arts-based methods can encourage reflection and help covering emotional and sensitive issues that might otherwise remain silent or underexplored. These methods also work well to make participants feel more at ease during an interview. The chapter will provide suggestions on how these methods could best be employed in a research study.

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1255

Keywords

Self-portrait · Relational map · Visual methods · Arts-based methods · Participatory research

1 Introduction

Visual, arts-based methods and other creative approaches to research have much to offer to qualitatively oriented researchers. It is fair to say that the qualitative research community has over-relied on interviewing as their main source of data. While nobody would wish to deny the wealth of information and insight one can gain from a good interview, it is also clear that the choice of the interview as an instrument of data collection comes with many methodological limitations. A research interview assumes that the participating people will be able and willing to verbalize their thoughts and views, and that they will be comfortable with face-to-face interaction with a researcher (Mason 2002a). These are rather big assumptions to make, which actually work to the exclusion of a significant part of the population. Many people will feel uneasy sitting in front of a researcher to talk and this may concern, among others, children and young people, people who are not confident with their language skills, such as migrants, or people with intellectual disabilities.

Criticism to the efficacy of standard social science methods to adequately appreciate the changing realities of contemporary societies has been rife in recent years (Law 2004; Savage and Burrows 2007). As Heath and Walker point out (2012), some of these critical voices seem to have missed the emergence since the turn of the century of creative approaches to research, particularly in the field of youth studies, where the widely recognized need for more apt methods to study young people's everyday worlds has pushed researchers to be inventive about their craft (Bagnoli and Clark 2010).

Methodological innovation has especially moved in the direction of a pronounced engagement with visual methodologies (Harper 2012; Rose 2012) and more recently in a surge of interest with sensory approaches to research (Pink 2009), which aim to rely on the senses as a whole, rather than assigning vision the status of the main and privileged channel in the construction of knowledge. As part of this search for creative methods, many researchers have looked at the arts as a source of inspiration to develop novel and unconventional ways to look at the world (Leavy 2009; Knowles and Cole 2008). An interdisciplinary approach to research methods design, which blends the social sciences with the arts, can enliven social science methodologies and attune them to register everyday experience with a richness of detail and insight that eludes more conventional approaches. As Back (2012) argued, more imaginative and “artful” methods can help widen the sociological imagination and can very importantly be of crucial assistance in the attempt to democratize the research process (see also ► Chap. 62, “Personal Construct Qualitative Methods”).

I see the arts as central to create participatory ways to do research, and my own interest in visual and arts-based methods has directly emerged from my commitment to

seek novel and better ways to promote research inclusion. My research work has focused on the investigation of identities, which I have carried out holistically and with a participatory approach. Self-portraits and maps, two of the visual methods that I have applied, and the two methods that are the focus of this chapter, were specifically designed for visual elicitation (Rose 2012). They were, therefore, thought for use within the context of an interview, in order to promote better participation and to improve the quality of data that could be collected within a face-to-face interview session.

Both these methods rely on the use of respondent generated images (Prosser and Loxley 2008). The possibility of using images that have been created by participants, either contextually or before the data collection event, is an important feature of these methods. The grounding of data collection on the basis of participants' own images goes to emphasize the contribution and involvement of the people who take part in research. From this perspective, even a very simple drawing task can take on a huge significance in terms of making participants feel that they can contribute to shape the project. This is a crucial point on several levels. First, it enables participants to make the project their own and feel that they can decide and direct its contents. It is one small but significant way in which the research process can be opened up and made more democratic, and participants can be assigned a leading role, rather than merely being viewed as passive objects of study.

Second, widening the research scope to nonverbal dimensions, in this case specifically a visual dimension, is crucial to the production of a different kind of knowledge, a knowledge that is holistic and does not privilege words as the main format for its construction, sharing, and communication. The design of multiple ways to take part in research, which do not necessarily rely on the assumption that verbal interaction with an interviewer will always be the most appropriate channel for the communication of experience, is finalized to reflect people's own preferred expressive styles and thus to encourage participation (Bagnoli 2009). The visual angle of the two methods discussed in this chapter was specifically aiming to appreciate even those dimensions of experience that are not easily put into words.

Reliance on a participatory framework means that researchers will attempt to follow participants' guidance and will consider them as the experts on their own lives. This implies for a research team engaging in active reflexivity throughout the research project (Mason 2002b), critically looking at their own assumptions and examining how their own social positioning impacts on the research process and locates them in relation to the participants. As some scholars have noted (Luttrell 2010), the application of participatory methods opens important issues with regards to how participants' views are then considered in the final reading and interpretation of results. On an analytical level, the reading of data should distinguish between participants' and researchers' meanings, and ideally, take both into account. In a participatory perspective, the effort to provide a transparent picture of any differences or clashes in interpretation should then be at the forefront, if we properly aim to engage in a co-construction of meanings and in a dialogical and reflexive process of knowledge building (Hesse-Biber and Piatelli 2010).

2 Self-Portraits

While working on the methodology for my PhD project on the process of identity construction in young people, I became critical of the efficacy of an interview to collect good quality, reflective data. In order to get a good understanding of identities, it was important to make sure that participants could feel at ease and encouraged to reflect about themselves and their lives. The design of a method which would provide the means, time, and space for participants to carry out this reflection was, therefore, a priority. This methodological research resulted in the design of a multi-method approach, which crucially involved the use of visual methods, including a technique of my own creation which I called self-portrait (Bagnoli 2004).

The self-portrait presents participants with a blank sheet of paper, colored felt-tips, and pens, with the request to show who they are at the present moment in their lives. Participants are then also asked to add anything that is important to them at that moment (Bagnoli 2004, 2009). The instructions are left deliberately open and general, and the method is designed to be unstructured, inasmuch as people are comfortable to take part.

The idea behind this task, which I usually introduced around mid-interview, after participants had already been prompted for narratives about their lives through both general and more specific questions, was to offer a chance to take some time away from the potentially stressful face-to-face interview context. Engagement with the self-portrait I thought could provide a creative opportunity to expand and think about other areas of life that might perhaps have been left aside in the interview talk. The self-portrait was, therefore, designed to be an ice-breaker, which might help participants feel more at ease, and a creative input to support in particular those who might not feel too comfortable with words when asked about personal and subjective issues, and might feel reassured by writing, drawing, or doodling as alternative forms of self-expression.

When designing this method, my own expectations had been that participants would produce some kind of plan or schema illustrating different aspects of their identities. The data collected in my PhD fieldwork, however, turned out to be rather different than what I had envisaged. While the self-portraits followed a range of styles on a continuum from writing to drawing (Bagnoli 2004), which also included some plans, it was clear that most participants, perhaps also because of the felt tips they had been given, had interpreted my instructions as a request for a drawing. The way in which participants will interpret instructions and relate to the method is important to consider. Any means provided will go to affect the kind of data that is collected and even the degree to which participants may be happy to engage with the task or not. These issues obviously need to be taken into account on the basis of the specific sample to be involved.

Within the context of my PhD investigation, one participant declined to make a self-portrait, the only one to decline on a total sample of 41. A middle-class, well-educated young woman and high-achieving university student, she manifested uneasiness at a method that she perceived as invasive and leading to a potential loss of control. Most participants, on the contrary, were happy to do the task, even

though they often felt they had to excuse themselves for their poor drawing abilities. Indeed, a potential problem with any drawing methods is that they may not be experienced as accessible enough. Providing reassurance that the artistic qualities of the portrait are not what one is after is important, as is clarifying that the “portrait” can in fact be made in any way one thinks best: a few key-words, a plan, or even an origami could have done just as well in my research. Such flexibility at the data collection stage then obviously needs to be reflected by an open mind also at the stage of analysis, with all that it concerns in terms of making sense of and integrating, or contrasting, mixed-source data within an overall interpretive framework.

The application of the self-portrait in the context of different research projects indicated that the type of data collected may vary significantly in relation to the sample involved. If the young people aged 16–26 of my PhD study had in most cases produced a drawing and had often even reported enjoying this task, with the younger sample that I involved in a more recent study (Bagnoli 2009), which saw the participation of 13–14 year-olds, drawing was even more predominant. The teenage sample did not need to justify themselves and were clearly more comfortable drawing, which appeared to be a task they were used to in their everyday life. On an analytical level though, this sample’s drawings often seemed to include more clichés and standardized images than the portraits produced by the older sample and were far more rigid in their color palette according to gender stereotypical norms (Bagnoli 2009, 2012): a red heart like that drawn by 26-year-old Johnny (Fig. 1) would with great difficulty have appeared in the portrait of a teenage boy. In this sense, the portraits could be telling about the visual culture of a population; in this

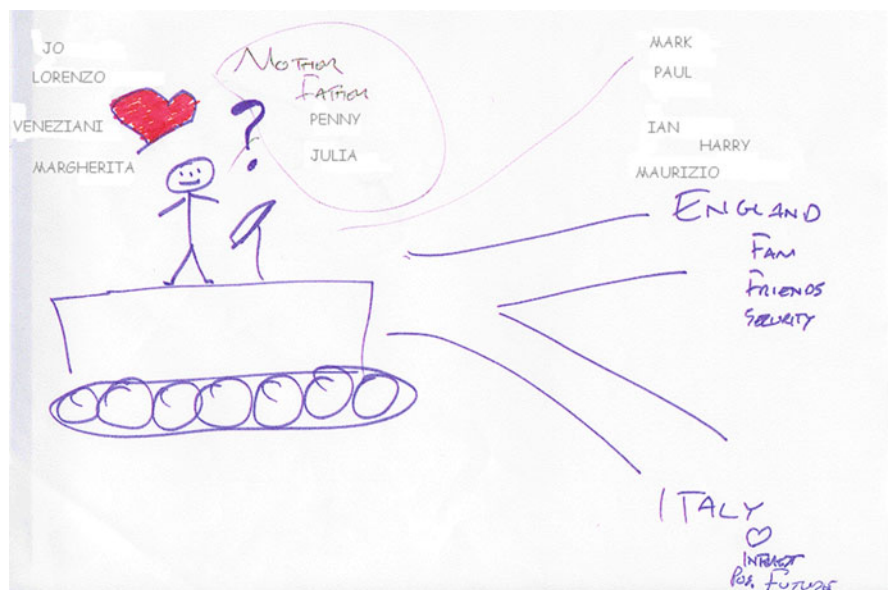


Fig. 1 Johnny's self-portrait

case a youth subculture. I noted, however, that it was with the older sample I researched that portraits seemed to have a deeper, more resounding meaning when read in context with the other biographical data collected.

The analytical value to attribute self-portraits has to be considered within the specific framework and aims of a research project. While obviously an example of visual data, a portrait is, however, more than just an image: it is a visual artifact produced in response to a researcher's request within a research interaction. It therefore carries with it also a link to verbal data, a narrative that is told contextually and which explains its meaning and the circumstances of its production. Analysis of self-portraits must note this connection and should pay attention to the researcher's role in their production. Portraits should, therefore, be looked at as data that are produced within the context of an interview situation and interaction.

The narrative collected at the moment of creation of self-portraits makes their meaning according to participants explicit. From a participatory point of view, this opens for people one channel to express their views from their own perspective. Qualitative research, however, is the art of interpretation, and there is usually more to meaning-making than a mere reliance on what is explicitly stated (Liamputtong 2013; Creswell 2014). While it is essential to make sure that participants can clearly communicate their message, interpretation does not just involve taking their words at face-value. The researcher's reading may point to other meanings in the portraits beyond what is said by participants and make connections to wider cultural repertoires. The analytical sensitivity one develops through the collection of self-portraits stimulates interpretation through comparison, with a focus that may be set on what is recurrent and what is not, what is contradictory, as well as what may be considered missing or unexpected.

As I have argued elsewhere (Bagnoli 2012), interpretation should best be considered as the result of a dialogue between researchers' and participants' views. A participatory perspective should, in my view, attempt to provide the instruments and possibilities for participants to effectively contribute to meaning-making, not only by providing their take on the world but also by getting the chance to comment on and respond to researcher's own interpretations. In this sense then, the construction of meanings may be seen as a collaborative effort, with the emergence and identification of different and even possibly divergent narratives from participants' and from researchers' perspectives.

Dedicated software such as Atlas.ti CAQDAS may be of great support in the analysis of self-portrait data. Its visual sophistication enables an easy coding of any images and facilitates the development of a coding structure that integrates visual as well as nonvisual data. In addition, it helps establishing hyperlink connections between visual and nonvisual data, such as between self-portraits and the narratives collected at the time of their production. Hyperlinks allow the simultaneous visualization of linked data and offer an alternative to explore the relationships among data to those researchers who do not wish to base their analysis on coding (Lewins and Silver 2007).

In my research experience, the self-portrait successfully aided the collection of reflective data and was an effective ice-breaker during the interview (Bagnoli 2004).

Some of the data provided by portraits were extremely useful in the construction of interpretations, and went on to acquire a driving role in the analysis, with the suggestion of insightful metaphors and powerful visualizations of what were participants' understandings of their own lives at that particular moment in time. The viewing of life as a journey, for instance, emerged as a widespread metaphor in my PhD data and was variously depicted in self-portraits through the images of a tree growing with fruits, a river running to the sea, one's self walking on a path or driving at a crossroads (Bagnoli 2012). See as an example Johnny's self-portrait in Fig. 1. Such images often corresponded to a prospective and fundamentally optimistic narrative about life, with an underlying idea of growth and development implicit to the narration of identity (Bagnoli 2012).

My PhD investigation included a longitudinal element, which required every participant to take part in two interviews. While for most people the time interval between the interviews was relatively short, of about 3 weeks' time, for some it amounted to up to 3 months. It was in those cases when the longitudinal interval was longer that the self-portrait demonstrated its interviewing potential. A few of these participants were by then living a very different reality from what they had shown in their portraits, which made these somewhat surprising, if not something they actively wanted to delete from their memory. Such was the case of Beatrice, who by the time of the second interview was in the process of divorcing her husband, who had instead been at the center of her self-portrait 3 months before (Fig. 2). The possibilities of applying a self-portrait in a longitudinal study are multiple and include, in addition to showing the portrait again at different times, asking for new portraits at different data collection stages.

This simple, low-tech method could lend itself to several potential applications, even with the use of different types of tools in place of paper, felt-tips, and pens. In

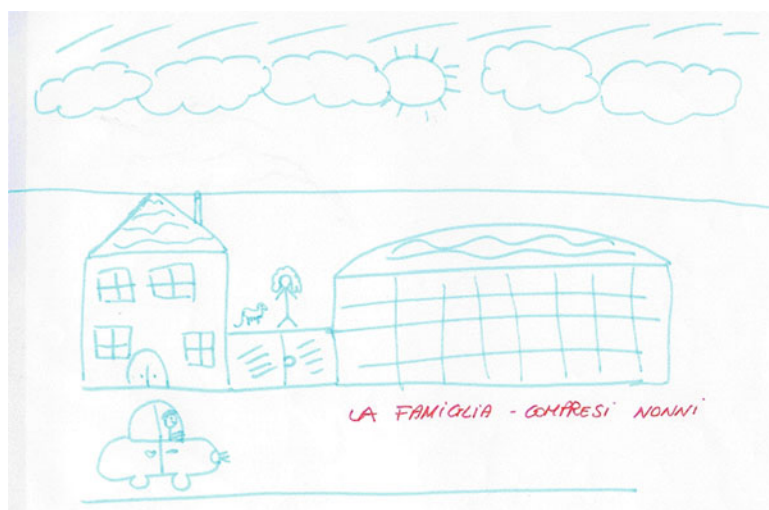


Fig. 2 Beatrice's self-portrait

my teaching of visual and arts-based research methods, I made a collective use of self-portraits and used this method as an ice-breaking task at the start of a training course, when asking participants to get to know each other and introduce themselves to the rest of the group. Group application in data collection could potentially be useful at the start of a workshop or focus group. While not everyone may be entirely comfortable with it, this is a creative method that can successfully collect novel and enlightening data.

3 Maps

The use of some form of maps during an interview can prove useful to help participants shape their thoughts and provide a narrative response to a question. Maps can be seen as visual scaffolding that support the construction of an answer and may also act as a memory aid, for both participants and researchers. Participatory mapping involves working with participants to collaboratively draw this map, relying as far as possible on participants' own ideas and links, as they emerge through the particular interview dialogue, rather than from a set of general and predefined research instructions valid for all (see also ► [Chap. 65, "Understanding Health Through a Different Lens: Photovoice Method"](#)).

My research experience with mapping has involved asking for maps to show the important relationships in someone's life. Several researchers have used some form of maps to study relationships, among them Josselson (1996) and Roseneil (2006). The simple model that I used in a study with English teenagers asked the young people to place themselves in the center of the map and then show the important others in their lives indicating the different degrees of their importance (Bagnoli 2009). No more specific instructions were given. I was interested in keeping the method as unstructured as possible, in order to provide participants the freedom to interpret my own broad guidelines as it suited them best.

One common type of map that was produced in response to these guidelines looked like the spider diagram drawn by Grace in Fig. 3. A type of map that is often requested in school work, the spider diagram was part of this cohort of young people's visual culture. As the contents of Grace's map indicate, with the inclusion of the Beatles and Bob Dylan, my own research also inquired for the importance of relationships with imagined others, people whom the young participants admired and who might not directly be part of their everyday lives.

As I have noted elsewhere (Bagnoli 2009), the request to place the self at the center of the map, and to differentiate the level of importance associated with each of the relationships considered, does however provide some assumptions with regards to how the map should be drawn. In order to minimize the structure that I was implicitly requesting from participants, in another application of this visual method, as part of a study investigating the identities of young Italian migrants to the UK, I simply asked participants to show who their important others were, without providing any further guidance. My interest here was studying these migrants' social networks and the extent to which they spread transnationally.

Fig. 3 Grace's relational map

The provision of a looser structure, however, can have quite the opposite effect of making the task less accessible to some people, as Riccardo, one of the Italian migrants, commented in his feedback:

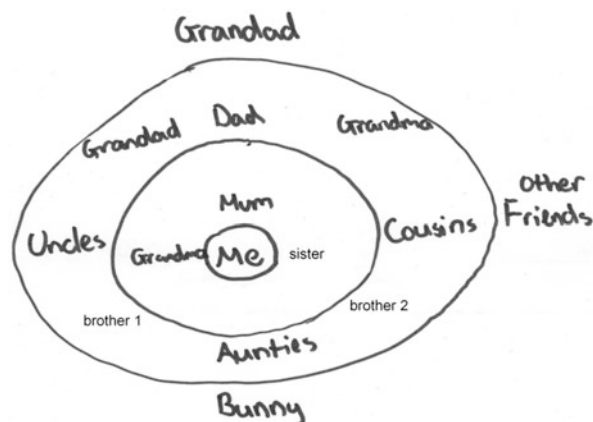
Probably you should give more detail, saying 'imagine you are in the middle, and then just list the things that are important to you, basically starting from yourself, from the first one to the last one, or vice versa' or stuff like that. It depends on your study. Because when you do a psychological study, this is important to see, my personality, everything, the way, how do I think. But if I have a different target, probably you should give more details about the map. Because I found it hard, because it was too open.

It is often the case that people will have a need for structure and certainties and will happily follow whatever format a researcher has predefined for the study. An open structure may make them feel disoriented and possibly exposed and vulnerable. It is interesting to see that Riccardo himself came up with the guideline to put the self in the center, as an indication that this specific format may be an intuitive and often used type of map in a variety of different contexts. When designing a map for a research study, it is, therefore, crucial to consider the map accessibility, and the degree to which the way the map is introduced may be inclusive and appropriate to the sample of people to involve.

My own experience with both relational maps and self-portraits indicated that these methods could be significantly more inclusive than other approaches with young people with intellectual disabilities. The open structure of the methods and the flexibility of the guidance I gave ensured that these young people could well relate to the task at hand and properly take part in the research project.

While a useful task to structure one's thoughts, a map can also perform well as an aide-memoire. This may be true for researchers, as well as for participants, who by paying attention to the drawing that is being produced during an interview may be able to better follow the thinking of the interviewee and notice whether some areas are adequately being covered or not, or may require further prompting or clarification. The map can, thus, provide an ongoing check on one's interview agenda, which may be especially useful in the context of a very long interview.

Fig. 4 Rebekah's relational map



My research with young people showed that a relational map was on some occasion crucial to collect sensitive data that had not previously sifted through by interviewing alone. This was the case of Rebekah, whose map follows the standard concentric circles structure which is widely used in research on relationships (see Fig. 4). Rebekah's map showed evidence of a side of her family, her father and her two step-brothers, who were not as close to her as other people in her everyday life. She remembered to include them and felt comfortable talking about her relationship to them only through engagement with this visual method (Bagnoli 2009).

While my own research has employed maps to inquire about relationships and social networks, maps could have a much wider use in connection to multiple areas of interest. Similarly to what I argued earlier with regards to self-portraits, longitudinal use of maps could be useful to check on participants' changing views and circumstances, and this could include both revisiting previously produced maps and asking for new ones to be drawn at different points in time.

Analysis of maps will consider what areas the participant has chosen to include and will have to be put in relation to any other data provided. Absences, as well as inclusion, will be very revealing, as well as the particular emphasis attributed to any specific item in the map. In addition to a case-by-case consideration, a cross-sectional look at maps could be very interesting. Comparison to other participants' maps could be analytically productive, and this comparison could even be carried out at the data collection stage. Showing participants someone else's map, or even an ideal-type map, which may for instance correspond to some extreme case, could give rise to pertinent probing questions and suggest further elaboration of answers.

Potential re-use of any maps will obviously have to take into account ethical issues, and it should be pointed out that anonymization of maps and drawings is far more straightforward than other visual data (Wiles et al. 2008). This will practically facilitate their further use in data collection, even with other participants or with a different sample, as well as their dissemination.

Group-based data collection could be thought of for maps too, particularly as a task to accompany a focus group. The map would in this case provide a basis for

sharing of participants' experiences and views, as well as an ice-breaking activity to promote group interaction. Just like with any other data, the interpretation of a map produced within a group session will have to take into account the particular data collection context. If the interaction with the researcher should always be kept in mind, for a map created in a group context the participation of a whole group in the activity and in the interaction will become salient.

4 Conclusions and Future Directions

This chapter has reviewed my research experience with two visual methods, the self-portrait and the relational map, which I have applied in the context of different research projects to facilitate elicitation during an interview and promote participation. Design of these methods was intended to provide a pause for reflection, a break from the interview interaction, and an opportunity for participants to give shape to and explore the unsaid, what they would not have yet had the chance to verbalize. Application in different projects proved both methods to be successful ice-breakers, which in most cases could enable participants to gather their thoughts and take time to develop their answers and thus engage in a wider and more reflective consideration of issues.

The visual scaffolding provided by these methods may be useful for participants to structure their thinking and may at the same time allow the researcher clearer access to their views. It can also usefully work as an aide-memoire for both parties in the interaction, particularly in the context of a long interview session. My fieldwork experience indicated that engagement with a visual task can even be a valid aid in getting participants to discuss potentially sensitive issues or other data that may not easily be collected through other, more standard methods.

In my design and application of self-portraits and relational maps I made a point to provide rather general, open instructions and keep the structure of any visual task as flexible as possible. The intention behind this was to enable these visual methods to adapt to participants' own expressive styles and to ensure inclusiveness. This flexibility was particularly successful to ensure the participation of children and of young people with intellectual disabilities. While it worked most times, it is important to consider that a loose structure can, not infrequently, be experienced as an obstacle by some people, who would prefer the reassurance of clear-cut instructions. It is obviously essential to adapt any methods to the specific sample to be involved in research. Flexibility and open instructions can facilitate the collection of participants' own preferred patterns and ultimately even provide an insight into their visual cultures. But it is important that a balance is struck with the need to design a method that is experienced as accessible by the target population.

Accessibility of methods should obviously be a fundamental point within a participatory approach to research. Several possible variations of self-portraits and maps may be thought in relation to different project needs, and longitudinal and even group applications may have considerable research potential. While the methods I

proposed in my projects were low-tech and of straightforward application, more sophisticated developments could be appropriate in other contexts.

Since these methods were thought for use within an interview setting, the interactional context in which they were applied should be considered when making sense of the data that they collected. Such data are obviously visual but also include the narrative data with which participants describe and explain what the images show. Analysis will have to look at the links between images and words, and at the contextual dialogue and interaction from which portraits and maps emerged. These data channel through participants' own understandings and their participatory design can make them an open window on their worlds and meanings. Interpretation does, however, involve something more than merely reporting participants' views and requires researchers to provide their own understandings as well, which may even contradict what participants say. The researcher's point of view is quite obviously privileged by the possibility of drawing comparisons between data and contrasting different visualizations and narratives and will be informed by references to the wider social and cultural context in which data are produced. It will, thus, be important in the analysis to recognize whose input is being followed, what views are coming from participants, and what from the researcher's own understanding, instead of assuming an unproblematic main voice that obscures different interpretations.

Recent methodological developments in the social sciences have increasingly shown attention for the potentialities of creative, sensory, and arts-based approaches to research. These innovative methods are often proposed within a participatory research framework. As it has been noted, the way project results are presented often lacks a true appreciation of the meaning of participation at different stages of the research process. This ultimately goes to the expense of participants' voices, which end up being deleted from view, in favor of the researcher's perspective which becomes the only version available. It is clear that, for the analysis stage to properly have a participatory approach, a huge amount of effort must go into making the process more democratic. Consideration of the impact of different research actors' perspectives on the interpretations we construct is but a start in this direction.

Finally, it should be said that the use of visual methods such as self-portraits and maps brings numerous exciting possibilities as far as dissemination is concerned. These novel methods also suggest creative and multimedia forms of outreach that can stretch far beyond the traditional academic outputs we are used to, and which can potentially have a much higher impact on the wider community, as well as offering additional forms of reward for participating people.

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Walking Interviews

72

Alexandra C. King and Jessica Woodroffe

Contents

1	Introduction	1270
2	Background to Walking Interviews	1271
3	Key Strengths and Characteristics of Walking Interviews	1273
3.1	Walking Interviews are Flexible, Adaptive, and Dynamic	1273
3.2	Walking Interviews Engage with Place and Encourage Collaboration	1275
3.3	Walking Interviews are Sociable and “Everyday” in Nature	1277
3.4	Walking Interviews Are Collaborative and Embodied	1277
3.5	Walking Interviews Are Compatible with Other Research Approaches and Methods	1278
4	Critical Considerations and Limitations of Walking Interviews	1279
4.1	Are Walking Interview Really “Natural” and Collaborative?	1279
4.2	Are Walking Interview Really Shared Experiences of Embodiment and Lifeworlds?	1280
5	The Practice of Walking Interviews: Advanced Techniques, Data Collection, and Other Considerations	1281
6	Walking Interviews in Practice: Introducing Mrs. Brown and Mr. Mitchell	1283
6.1	Walking with Mrs. Brown	1283
6.2	Walking with Mr. Mitchell	1284
6.3	Reflections on the Case Studies	1286
7	Conclusion and Future Directions	1287
	References	1288

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1269

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Abstract

Walking interviews or “go-alongs” are an innovative qualitative research method which has recently gained popularity among cross-disciplinary researchers. Walking interviews entail researchers and participants talking while walking together. Informed by “the new mobilities paradigm” and “the spatial turn” within the social sciences, this method has been employed in various settings and with participants of all ages. Walking interviews are a valuable means of deepening understandings of lived experiences in particular places. The rich, detailed, and multisensory data generated by walking interviews demonstrates that they are a valuable, valid, feasible, and empowering means of conducting qualitative inquiry. They can also be employed concurrently with other qualitative methods such as in-depth interviews and ethnographic observation. The use of walking interviews in health research, with its potential to capture the lived experiences of health and illness, has so far been relatively limited. This chapter introduces the reader to the walking interview method, provides practical guidance for its use, outlines epistemological, ethical, and practical considerations for researchers, and canvasses its varied applications for qualitative health research.

Keywords

Walking interviews · Go alongs · Mobile research methods · Mobilities · Emplacement

1 Introduction

Walks. The body advances, while the mind flutters around it like a bird.

~Jules Renard, 1907 (Renard 2008, p. 266)

Human mobility, specifically achieved through the act of walking, is a somewhat habitual and taken-for-granted part of our individual experience and social existence. For those who are able, walking enables and presents many constant and unique opportunities and meanings on a daily basis. On one hand, it allows for physical movement through and among space and place and is seen to promote physical health and well-being. On another, it can be used for autonomy, reflection, and solace or for interaction, companionship, and social activity. Often the subject of poetry in decades past, in recent years, three major movies have been released which center on a transformative, long walk taken by its protagonists – *The Way* (2010) with Martin Sheen, *Wild* (2014) with Reese Witherspoon, and *A Walk in the Woods* (2015) with Robert Redford. This recent preoccupation with the symbolism of a long walk as a personal inner journey or a pilgrimage among filmmakers has arisen in parallel with a burgeoning interest among researchers in utilizing walking as a research method, aiming to enter new landscapes for generating understanding within qualitative enquiry.

Walking interviews are a relatively new and innovative qualitative method, with roots in ethnography, anthropology, and geography, which can effectively

minimize some of the perceived limitations of more traditional, stationary sit-down interviews. Referred to by a variety of terms including “walk-alongs” and “go-alongs,” walking interviews largely involve a researcher walking with one or more participants while conducting an interview. As a natural fusion of interviewing and participant observation, walking interviews are a powerful and unique method for engaging with space and place, and the important and nuanced meanings, experiences, values, and understanding of individuals in these domains. While used effectively within the disciplines of geography and social sciences for some time, the opportunities and strengths of this relatively new method to the health sciences are only now starting to emerge. This chapter calls for a greater appreciation that experiences and meanings of health, well-being, and illness at both community and individual levels can be explored and illuminated through this method.

The chapter introduces the reader to the method, outlining its key features and canvassing its varied applications for qualitative health research. It provides practical guidance for employing it in fieldwork, outlining some epistemological, ethical, and practical considerations for researchers. The key aims of the chapter are to:

- Provide some background and context to the emergence of the method
- Situate the method within methodological and theoretical approaches
- Provide consideration of the strengths and advantages, weaknesses, and limitation of the method
- Look at its compatibility and use with other research methods
- Briefly explore the key issues and practicalities of using the method
- Provide case study examples of walking interviews in practice
- Canvas areas in which this method could be used productively with the health and social sciences

2 Background to Walking Interviews

Life itself is as much a long walk as it is a long conversation, and the ways along which we walk are those along which we live ~ Tom Ingold & Jo Lee Vergunst (Ingold and Vergunst 2008, p. 1)

A walking interview is a qualitative research method with roots in ethnography, anthropology, and geography, which involves a researcher walking with one or more participants while conducting an interview (see also ► [Chap. 26, “Ethnographic Method”](#)). They are naturally person-centered and interactive and are designed to understand human experiences and social action (Kusenbach 2012). Writers and academics have sought the generative effects of walking in their work for centuries, including the walking philosophers of the Aristotelian school in Ancient Greece, and the Romantic poets Wordsworth and Coleridge, who took long walks in the countryside to nurture their writing (Solnit 2001). In the early

twentieth century, walking was perhaps first used as a research method by the Chicago School of sociologists, who conducted mobility studies of homeless men, street gangs, and sex workers (Büscher and Urry 2009), and for seminal ethnographies by Clifford Geertz, who used walking during his phenomenologically inspired fieldwork in Indonesia (Jackson 1996).

The burgeoning interest in employing walking interviews for empirical research was borne from the emergent field of mobility studies. Informed by “the spatial turn” in social sciences and the increasing mobility of human societies (Ricketts Hein et al. 2008), this enhanced attention on mobility as a key part of contemporary life has been labeled “the new mobilities paradigm” (Sheller 2014, p. 789). It is a diverse field, traversing the disciplines of geography, ethnography, sociology, transport, and tourism, and even sports studies and arts practice. Utilizing different forms of movement, mobility studies explore a variety of mobilities, ranging from those which are mechanized and global such as air travel, to those which are embodied and local such as walking (Cresswell 2012).

In recent years, researchers have employed a diverse set of mobility-focused methods and approaches, which can be loosely categorized according to whether the researcher remains stationary and observes participants’ movements, or instead goes “on the move” alongside participants, whether in trains, cars, or on foot (Ricketts Hein et al. 2008; Büscher and Urry 2009). Within walking studies, a distinction can be made between those studies which employ walking methods to explore a range of phenomena other than walking, and research which focuses on walking itself, such as those conducted into the walking practices of children (Horton et al. 2013). And finally, a further distinction can be made between walking-based methods in which a participant primarily narrates a walk while accompanied by a researcher such as a guided tour, or those studies in which a participant primarily answers a researcher’s questions, such as a walking interview (Stroud and Jegels 2014).

Researchers apply a variety of labels to walking interviews but perhaps the most common alternative label is “go-alongs” (Kusenbach 2003; Carpiano 2009; Bergeron et al. 2014). Other more idiosyncratic terms include “walk-alongs” (Rose et al. 2010), “mobile interviewing” (Brown and Durrheim 2009), “walking probes” (De Leon and Cohen 2005), “walking fieldwork” (Irving 2010), “dwelling-in-motion” or “stretched out belonging” (Edensor 2010), “walking with’ ethnography” (Peyrefitte 2012), “shadowing” (Jirón 2010), and finally, more playful terms such as “pedestrian enquiry” (Hall et al. 2009) and “pace in place” (Hitchings and Jones 2004) (see also ► Chap. 73, “Participant-Guided Mobile Methods”).

Walking interviews are compatible with a number of traditions within interpretative and constructionist research approaches which aim to understand human behavior and experiences from the viewpoint and interpretations of those being studied, including phenomenology, social constructionism, ethnography, participatory and action research, feminism, and critical theory (see also ► Chaps. 26, “Ethnographic Method,” and ► 17, “Community-Based Participatory Action Research”).

3 Key Strengths and Characteristics of Walking Interviews

...the moment my legs begin to move, my thoughts begin to flow.
~Henry David Thoreau, 1851 (Thoreau 1960, p. 64)

There are many characteristics of walking interviews which make them innovative, unique, and worthy of consideration in the design of new qualitative enquiry. This section presents an overview of some of the key merits and strengths of walking interviews, including the flexibility of the method and its dynamic and adaptive nature, its ability to capture meaning while “in-place” and in the everyday context, its collaborative, sociable, and embodied nature and its compatibility with other methods.

3.1 Walking Interviews are Flexible, Adaptive, and Dynamic

Walking interviews are a flexible, adaptive, and dynamic research method. Unlike traditional sit-down or sedentary interviews, walking interviews literally transcend the boundaries of interview rooms and move the art of conversation and qualitative interviewing to the “outside.” During walking interviews, participants can provide not only recollections of place but also experience and describe immediate “rich and varied perspectives of environment” (Garcia et al. 2012, p. 1) stimulated by the simultaneous act of walking and talking.

Walking interviews are readily adaptable to different local contexts, research topics, and participants’ needs. Variations of the method might involve participants narrating their thoughts about the unfolding environment while walking (Irving 2010) or participants taking the researcher on a guided tour of a particular locality or setting (Carpiano 2009; Garcia et al. 2012). Walking interviews can be used to explore a variety of phenomena in a range of settings including people’s feelings about large shopping centers in the United Kingdom (Rose et al. 2010), residents’ perceptions of their neighborhoods (Kusenbach 2003), people’s perceptions of local parks and streets (Moles 2008; Vergunst 2010), and intersections of ethnicity and place in South Africa (Brown and Durrheim 2009). In qualitative health research, walking interviews have been employed to enquire into health inequalities in neighborhoods (Carpiano 2009), an experience of being diagnosed as HIV positive (Irving 2010), the sexual health resources available on a university campus (Garcia et al. 2012), and older adults’ experiences of eating and aging in rural Australia (King 2014; King et al. 2015).

In the burgeoning area of qualitative health research, uncovering the meanings which are attached to people’s lived understandings of health and illness, including their experiences of health and social care, is now acknowledged as contributing to evidence-based practice (Liamputtong 2016, 2017). While health research has traditionally been dominated by biomedical and reductionist discourses of health which are focused on medicalization through diagnoses and cure (Nettleton 2013), there is increasing interest in engaging with the multifaceted experiences, feelings,

emotions, and meanings of individuals for understanding health and illness (Grbich 1999; Liamputtong 2013; Green and Thorogood 2014). In this regard, the flexibility and dynamic nature of walking interviews within qualitative enquiry offers opportunities for health researchers to incorporate explorations of space and place and the meanings attached to particular settings and contexts (e.g., hospitals, outpatient clinics, waiting rooms, parks or recreational spaces, or community infrastructure) into studies which aim to develop understandings of individuals' lived experiences of their health and environment.

Walking interviews provide researchers with unique opportunities to describe the setting and contexts of research, as well providing insight into environmental and locational influences that can impact significantly on how individuals perceive, experience, and exercise agency over their wellbeing, health, and care. As Garcia et al. (2012, p. 2) argue, walking interviews assist in capturing "the natural relationship between health and place in a participatory manner." Walking interviews have also proven to be feasible and effective in research conducted with people of different ages, including children (Hitchings and Jones 2004), young people (Anderson and Jones 2009; Hall et al. 2009; Ross et al. 2009; Garcia et al. 2012; Holton and Riley 2014), and older adults (Riley 2010; King 2014).

Researchers have also noted the usefulness of walking interviews for conducting research with hard-to-reach and mobile populations, including disengaged youth and homeless people (Ross et al. 2009) who may be reluctant, intimidated, or simply unable to participate in "traditional" research conducted outside of their immediate environments which offers them security, safety, or meaning. Similarly, the simple practice of "going to" people and speaking with them while they interact with others and move about within their own environments, so as to explore experiences, ideas, and constructions of place, has been used by the authors during participatory research into a number of areas, including social inclusion, health promotion, aging, youth engagement, and local government planning, in which place-based participatory research is valuable and effective.

By moving out of the confines of the interview room, walking interviews "allow the environment and the act of walking itself to move the collection of interview data in productive and sometimes entirely unexpected directions" (Jones et al. 2008, p. 8). Walking interviews are often dynamic in nature and do not strictly adhere to methodological rules, such that the exact route, walking pace, duration, mood, and content of the interview often unfolds "on the go" in response to the changing landscape, weather, interactions with other walkers, or other unplanned events (Jirón 2010). This gives walking interviews a style which is more improvisational than highly structured or predetermined.

Walking interviews also inform the nature of the research encounter by "loosening up" the interview experience, allowing data to be more readily elicited. Both spontaneous talking and questions tend to arise more often, stimulated by the changing environment, such that interviews often flow more easily, with fewer awkward gaps in dialogue than might occur in more traditional, sit-down interviews (De Leon and Cohen 2005; Ross et al. 2009; Riley 2010; Evans and Jones 2011). This method tends to generate a more natural or conversational style of interview.

The “plethora of encounters, diversions and disruptions” that comprise a walking interview allows the conversation to naturally move between topics and moods, “incorporating the intimate and the mundane, the near and present, remembered and imagined in the free flowing movement of the walk and talk” (Ross et al. 2009, p. 619).

3.2 Walking Interviews Engage with Place and Encourage Collaboration

Walking interviews are sensitive to local context; they enable researchers to simultaneously engage with people and the places that have meaning within their lives. Conducted in situ, they deeply engage with concepts of place and thus provide qualitative researchers with an invaluable opportunity for generating rich and unique data. Walking and talking in different settings opens up opportunities to understand the complex, multilayered, and textured social world of individuals sought by qualitative researchers (Mason 2002).

In doing so, walking interviews assist in overcoming one of the key disadvantages of traditional sit-down qualitative interviews which take participants away from their day-to-day activities and locate them within a highly constructed dialogue setting which can inhibit natural conversation, stultify interaction, and thus constrain the building of rapport and trust advocated for and sought by qualitative researchers. In contrast, locating research encounters in outdoor or recreational spaces can help to generate relaxed interactions and dialogue between researchers and participants, which can more readily produce unstilted and spontaneous verbal data (Ricketts Hein et al. 2008). These places do not need to be publically significant or monumental in any way, as the “mundane locations and the events that occur at them can elicit rich responses” (De Leon and Cohen 2005, p. 201). In our own research, the use of walking interviews allowed older adults to share their valued places, for example, their homes, gardens, and towns. This method helped to create an atmosphere which allowed the researcher to appear and feel like a friendly visitor in participants’ lives and less like an interrogator or indifferent observer.

As well, separating people from their natural environments runs the risk that “important aspects of lived experience may either remain invisible, or, if they are noticed, unintelligible. This is especially true for the spatial footings of experience and practices in everyday life” (Kusenbach 2003, p. 459). By situating people in particular places, walking interviews produce a “decidedly spatial and locational discourse of place”, in which participants can readily talk about the places in which they live or act (Evans and Jones 2011, p. 856). Participants’ oral histories or personal biographies tend to unfold more easily during walking interviews than sit-down interviews. Their recollections may be stimulated by the surrounding environment, such as old buildings they have worked in or houses of former friends, such that “the spaces prompt recollection of place attachment, demonstrating an active connection between body, landscape and memory” (Jones and Evans 2011, p. 2323; Kusenbach 2003; Vergunst 2010). Walking interviews thereby produce accounts that constitute an “interweaving of personal biography and individual

experiences with collective (social) memories and spatial histories” (Clark and Emmel 2010, p. 5). This aspect of the walking interview method makes it particularly valuable for research with people who have longstanding work or family ties to a particular area, such as farmers (Riley 2010).

In our above-mentioned research with older adults, participants were readily able to point out changes in place and space, including changes to streetscapes, landscapes, weather, or gardens, most of which were intimately connected with significant people or events in their everyday lives, both past and present (King 2014). In this sense, walking interviews can be said to encourage participants to express “place-bound meanings and values of places”, thereby revealing personally held and highly localized “micro-geographies of meanings” (Bergeron et al. 2014, p. 108). As such, they are a “unique tool for examining how physical, social, and mental dimensions of place and space interact within and across time for individuals” (Carpiano 2009, p. 264), which allow researchers to examine, first-hand, the informant’s experiences, interpretations, and practices within their environment.

In one of the earliest articles on walking interviews as a research method, the sociologist Margarethe Kusenbach explicitly linked walking interviews with phenomenological research enquiry. Kusenbach argued that by “exposing the complex and subtle meanings of place in everyday experience and practices, the go-along method brings greater phenomenological sensibility to ethnography,” thus labeling the method “street phenomenology” (2003, p. 455). Certainly, walking interviews support phenomenological concerns by generating deeper understandings of unique and meaningful relationships between people and particular places (Moles 2008). As such, walking interviews help researchers to explore phenomenological notions of emplacement and nonrepresentational theory, which are concerned with embodied and sensory experiences of place (Casey 1996; Jackson 1996; Thrift 2008; Vergunst 2010). A walking interview is a multisensory research encounter for both participants and researchers, in which landscapes and streetscapes are seen; pavement or soil is felt underfoot; odors and aromas of gardens, streets, and farms are smelled; and background noises of birds, children playing, or cars are heard (Anderson and Jones 2009; Ross et al. 2009).

Perhaps arising from these kinds of sensory experiences, walking interviews readily elicit participants’ verbal expressions of emotions and affect about particular places. In research into visitors’ experiences of a botanical garden, participants found it easier to verbalize their feelings during their walking interviews than in their earlier sit-down interviews (Hitchings and Jones 2004). In another study, walking interviews helped uncover the emotional ties that young people had to particular places, with the researchers noting that these kinds of “individualized meanings and identifications often remain out of view through other techniques” (Anderson and Jones 2009, p. 299). The enhanced capacity of participants to express their emotions which is evident during walking interviews grants researchers valuable opportunities to engage, albeit temporarily, in the experiential lifeworld of their research participants, by sharing in their sensations and witnessing their emotions (Rose et al. 2010). In research conducted with a young man recently diagnosed as HIV-positive, walking fieldwork effectively uncovered “realms of inner expression” that might have otherwise remained hidden (Irving 2010, p. 34).

3.3 Walking Interviews are Sociable and “Everyday” in Nature

Walking with others is a profoundly social activity which requires close awareness of another’s movements while also engaging in conversation (Ingold and Vergunst 2008), and it is such a common practice among humans that it is arguably “fundamental to the everyday practice of social life” (Lee and Ingold 2006, p. 67). The deeply social nature of walking aids the mood of a research interview. Walking interviews are, in this sense, a socially familiar method; when visiting a friend, one might take a conversational walk around their property or neighborhood, which is not altogether dissimilar to a walking interview.

Importantly, a walking interview also has a particularly prosaic, everyday or pedestrian content or character which is generated by “talking on the go, moving through local spaces amidst all the mundane distractions and reassurances of place” (Hall et al. 2009, p. 552).

The method thus illuminates the “incidental, trivial, mundane and often dull dimensions” of phenomena which are enacted in place but are not necessarily readily verbalized during traditional sit-down interviews (Anderson and Jones 2009, p. 299).

3.4 Walking Interviews Are Collaborative and Embodied

Walking interviews have greater potential for collaborative construction of meaning and enquiry between researchers and their participants, than other more sedentary, sit-down interviews provide. It is important here to make a clear distinction between walking-based research methods (Evans and Jones 2011) and conducting research while mobile, such as “ride-alongs” in cars (Büscher and Urry 2009). Arguably, walking interviews are qualitatively different because walking is an active, embodied practice which contrasts with undertaking mechanized travel, during which one is essentially sedentary while in motion (Edensor 2010; Evans and Jones 2011). Various experiential benefits have been attributed to the physicality of walking, and it is thought to impact directly upon the experience of the interview. While Solnit (2001) argues that “. . .the rhythm of walking generates a rhythm of thinking” in walkers, others see walking’s effect as more metaphorical than physical: “through walking, the researcher and the participant bumble into new narratives, and discover and construct new spaces together as a result” (Moles 2008, p. 13).

Certainly, as a shared corporeal or bodily experience, the physical act of walking alongside someone shapes the research encounter, aiding the development of an intersubjective understanding of the physiological particularities of a respondent’s lifeworld (Pink 2007). Unlike a more traditional interview, the researcher and participant are side-by-side rather than face-to-face, such that direct eye contact is reduced but their view is now shared (Lee and Ingold 2006; Lorimer 2011). Through side-by-side engagement and a shared experience of sensory data, this method allows for a deeper understanding of the “here and now.” For example, a participant being able to physically show the researcher where and why they feel unsafe in a public space enables the researcher to share in the emotions of the participant, as well

as being able to physically experience the setting for themselves. As such, it moves beyond a recollection and explanation of space and place, to one which is real, “in-time” and observable, and serves as a point of further conversation. This arguably facilitates a greater empathic and collaborative encounter, in which each other’s experiences and emotions are understood, acknowledged, and shared.

As well, walking together further aides collaboration by generating a sort of intimacy or empathy, as the shared practice “gives an immediacy as well as a kinaesthetic rhythm which makes for a different experience” between researcher and participant (Evans and Jones 2011, p. 850). This effect is reciprocal, such that “the walk shapes the rhythm of the talk, and the talk shapes the rhythm of the walk” (Lorimer 2011, p. 29). A degree of sociability is engendered by walking with another person, perhaps arising from the physical and cognitive process of developing a shared walking rhythm (Lee and Ingold 2006), thus enabling a form of collaborative interaction.

Walking interviews can thus serve as a “rapport builder” (Carpiano 2009, p. 67), working to minimize any discomfiting differences in education, age, ethnicity, or gender between researchers and participants. Walking interviews can also partially “disrupt” traditional power relations within research or at least serve to encourage a more collaborative approach. The nature of the method allows for participants to become at least partial collaborators in the research, effectively co-generating meaningful data while engaging in a mutual dialogue with researchers, rather than merely responding to questions in an interrogation (Jones et al. 2008; Moles 2008; Brown and Durrheim 2009; Carpiano 2009; Clark and Emmel 2010). The flexible nature of walking interviews also allows researchers to cede some power or influence to participants in fieldwork, by inviting them to choose the walking route, determine the pace of a walk, avoid particular areas, or interrupt an interview to talk to other pedestrians encountered during the interview (Hall et al. 2009; Ross et al. 2009).

3.5 Walking Interviews Are Compatible with Other Research Approaches and Methods

As an amalgam of observation and traditional sit-down interviews, walking interviews offer new opportunities for qualitative researchers who want to explore, through movement and conversation, more multilayered and complex meanings and experiences within an individual’s social world (see also ► [Chap. 73, Participant-Guided Mobile Methods](#)). As such, they are suitable for both qualitative and mixed method designs and for use with other methods of data collection including surveys, focus groups, observations, and also repeat or serial interviews (see also ► [Chaps. 63, “Mind Maps in Qualitative Research,”](#) and ► [4, “The Nature of Mixed Methods Research”](#)).

The last of these methods have been used in the social sciences for some time but remain relatively underused in the health and medical sciences (Murray et al. 2009). As a method, repeat interviews involve speaking with participants repeatedly over a period of time, usually months or years. Doing this provides more than a single snapshot of time, feeling or meaning, instead allowing researchers to explore

changes in needs and experiences of people over time (Murray et al. 2009; King 2014) and to develop a closer relationship with participants, opening up greater rapport and trust. Within qualitative longitudinal health research, serial interviews have been fruitfully used to understand the shifting experiences and needs of people with progressive diseases such as lung and brain cancers, diabetes, and cardiac failure (see Murray et al. 2009 for examples).

The use of serial walking interviews alone or in combination with serial sit-down interviews is almost non-existent in the literature but offers great potential for the field of qualitative longitudinal enquiry into health. We have used walking interviews in combination with serial sit-down interviews to explore the meanings of food and aging in older rural Australians (King 2014). The study, using a phenomenological ethnographic design, showed that the passage of time within particular places significantly underpinned older adults' basic sense of confidence in themselves, which informed their food security and health and well-being while aging (King 2014).

Other researchers have combined walking interviews with various technologies, including photography, a variation of Photovoice (Irving 2010; Peyrefitte 2012; Bergeron et al. 2014; see also ► Chap. 65, "Understanding Health Through a Different Lens: Photovoice Method"), geographic information systems (GIS) mapping of walking routes (Jones et al. 2008; Bergeron et al. 2014), video ethnography (Pink 2007), and even bio-sensing, with heart-rate monitors worn by participants (Spinney 2014).

4 Critical Considerations and Limitations of Walking Interviews

I have walked myself into my best thoughts. . .

~Soren Kierkegaard, 1847 (Poole 1993, p. 172)

Although walking interviews have been written about in very favorable terms in recent years, additional rigorous examination of the benefits that this method brings to research encounters, over and above those of more sedentary methods, is warranted (Ricketts Hein et al. 2008; Merriman 2014). While this chapter highlights the innovative nature of walking interviews as a method and their potential for use in health and social sciences, there are also some key issues when considering the use of this method, from both a theoretical and practical perspective. Engaging in this critical reflection prompts several key issues for consideration by researchers when incorporating this method into health research frameworks and designs, as well as in regards to data collection.

4.1 Are Walking Interview Really "Natural" and Collaborative?

While there are many ways in which walking interviews can create greater ease and dialogue between researcher and participant, walking interviews are not entirely

natural encounters because, like sit-down interviews, they are almost always planned, contrived, or “managed” events because the researcher has initiated the activity with the participant (Kusenbach 2003) and hence, “it can never be completely spontaneous” (Bergeron et al. 2014, p. 120). However, there is a kind of sliding scale of contrivance for walking interviews. At one end, there are guided tours of a city which are requested of participants by researchers, and at the other, researchers walking alongside participants while they walk a usual route as part of their usual routine (Kusenbach 2012).

Additionally, there is a need to acknowledge that all interactive research encounters, regardless of intent, inherently involve a power imbalance and that active reflexivity is required on the part of the researcher to minimize this as much as possible. It is well recognized among qualitative researchers that “the researcher is in a relatively powerful position vis-à-vis the interviewee” (Green and Thorogood 2014, p. 110). While this may not always be the case (e.g., when interviewing powerful or elite people), most interviews for health research do involve a power imbalance between researcher and interviewee which is generated in part by social differences, including socio-economic status, race and ethnicity, gender, and age (Grbich 1999). Even in cases where such characteristics are shared between researcher and participant, and thus assist in developing rapport and trust, the actual act of “being” the interviewer and initiating the interview through engaging in recruitment, obtaining consent and the formalities of asking questions, arguably still involves power and a level of perceived authority, which may inhibit the discussion and relationship.

While qualitative researchers generally strive to empower participants, and adhere to ethical standards of consent and the right of participants to withdraw from research, it is important to understand that with a walking interview, it might be more difficult or uncomfortable for a participant to stop an interview because of discomfort or discontent with the process, especially if a significant distance has already been traversed. As with all interview processes, power issues may be obvious within the walking interview; however, power may also be nuanced, subtle, and submerged – so much so that they may not become apparent to the researcher until after the walking interview is conducted. Significant power imbalances may be minimized through reflexivity on the part of the researcher and the use of serial interviews in order to develop trust between participant and researcher. To aid reflexive awareness, it may be useful for researchers to not only take field memos after walking, but to transcribe the walking interviews immediately after they are conducted (and before any others are conducted) in order to reflect on issues of power.

4.2 Are Walking Interview Really Shared Experiences of Embodiment and Lifeworlds?

The capacity of walking interviews to provide access to another’s lifeworld is also worthy of critical reflection, particularly when applied in research informed by phenomenology. Some researchers have argued that walking interviews allow them to temporarily “live” participants’ lives or even inhabit their bodies (Pink

2007; Anderson and Jones 2009; Rose et al. 2010). This is a significant epistemological claim which provokes questions about whether it is ever possible, even temporarily, to inhabit the body and life of research participants.

Phenomenological researchers Lee and Ingold (2006, p. 67) assert that “walking does not, in and of itself, yield an experience of embodiment”, because this presupposes a level of shared bodily circumstance between researcher and participant which does not often exist. For example, in research with older adults described in the case studies below, the walking interviews revealed disjunctive rather than mutual corporal experiences. These provided insights into the participants’ embodied life experiences, but did not extend to any sense of inhabiting their bodies or living their lives. Similarly, in “shadowing research” undertaken in urban Mexico, the researcher distinguished between achieving a closeness with participants’ mobility and fully sharing in their existence, asserting that “. . .this ‘being’ is always someone else’s” (Jirón 2010, p. 36). While it is not clear that walking interviews can produce fully shared, embodied understandings of others, it is nevertheless a valuable research method because it “opens up the possibility of other types of knowledge and appreciation that do not presuppose commonality” such as empathic understanding (Irving 2010, p. 35).

5 The Practice of Walking Interviews: Advanced Techniques, Data Collection, and Other Considerations

This section moves to practical considerations for conducting walking interviews. It notes that the method is an advanced technique which requires careful research practice in relation to the collection of data and the ethical involvement of participants.

Walking interviews are challenging to conduct and thus can be considered an advanced or complex qualitative research technique. Several tasks need to be successfully performed simultaneously which call on a researcher’s physical, social, and cognitive skills. These include walking along a perhaps unfamiliar walking route, establishing and maintaining rapport with a participant, guiding the content and direction of the interview, noting the unfolding external environment, being aware of any physical, emotional, or mental discomfort of participants, negotiating a balance between a conversational and interview style of encounter, and responding flexibly to unexpected events, such as encountering neighbors or acquaintances. As such, walking interviews are perhaps better suited to researchers with some prior experience of conducting more traditional sit-down interviews. Even then, when undertaking this method for the first time or with an unfamiliar participant group, researchers might benefit from conducting several practice or trial walking interviews in order to hone their skills.

Walking interviews also pose challenges associated with data collection. As they are usually conducted outside and always conducted on the move, it is important to consider a number of issues. The first of these relates to capturing spoken words. Almost always, walking interviews are digitally recorded, rather than relying on field

notes or memory, as writing while walking is rather awkward and memory is fallible. Recording technology has improved considerably in recent years, but it is important to obtain compact, lightweight digital recording equipment which has a sensitive microphone. Researchers may provide participants with a small lapel microphone or merely hold the recording device near to them. Wind and other sources of background noise such as loud traffic or music, which might obscure recorded speech, need to be taken into account when deciding when and where to conduct walking interviews.

Beyond recording the spoken words of participants, additional decisions need to be made in relation to collecting the spatial or place-based data generated by walking interviews. For example, researchers might wish to note particular locations during the walking interviews, so that during analysis, spoken words can be linked with particular places that are meaningful, for example, a cemetery or a tree. This might be done verbally during the walk, or by writing a brief note in a small notebook during the walk, or soon afterwards by making notes at time stamps in the transcript while listening to the recording. Other methods include using GIS devices to generate maps or taking photographs to generate visual images of the walking route taken. However, it is worth noting that while gathering this additional data can generate rich fieldwork results, it can also significantly complicate and magnify the work of data analysis and the presentation of findings.

As with all valid qualitative research, careful consideration should be given to both the practicalities of the method and the ethical principles behind conducting research, including respect for human beings, research merit and integrity, justice, and beneficence, all which help to shape the relationship between researcher and participant as one of trust, mutual responsibility, and ethical equality. In any qualitative research, the particular characteristics and needs of participants should be closely considered, especially when researching sensitive topics or engaging with vulnerable populations (Mason 2002; Liamputtong 2007; Green and Thorogood 2014).

Most ethical considerations for conducting walking interviews are shared by sit-down interviews. These include obtaining informed consent, being sensitive to the burden placed upon respondents' time and energy by the interview, being aware of the risk of emotional harm from respondents recalling and recounting negative experiences or emotions, and acknowledging any issues of confidentiality and anonymity (see also ► Chap. 106, "Ethics and Research with Indigenous Peoples"). In addition, walking interviews require researchers to consider a couple of ethical issues which are specific to walking-based methods.

Firstly, there is a small but not insignificant physical risk to participants (and possibly the researcher) from engaging in walks, particularly when participants are very young or old, unwell, or mobility-constrained; or when walks are conducted in insecure neighborhoods, on unsafe paths, or during inclement weather. In our recent research with older adults, we were cognizant of these risks and responded by incorporating significant flexibility in the research method. Depending on their personal circumstances, we either agreed with participants on a walking interview with a route and duration that was appropriate to their health, mobility, and level of interest in the activity, or for other participants, we invited them to consider declining a walking interview altogether and to opt instead for a sit-down interview (King 2014). There is no optimum length of time or

distance for a walking interview; as illustrated in the case studies below, the distance, pace, and duration of walking interviews can be readily modified to meet participants' needs without impinging on the quality of the data generated during the research encounter. Indeed, short walks with many stops along the way may yield just as much high quality data as longer walks without breaks do, because the method's generative power lies in the shared mobility, experiences of place, and dialogue between researchers and participants, rather than the walk's duration or distance.

Secondly, both researchers and participants need to be aware that the confidentiality of participants' engagement in the research might be compromised during walking interviews in public places, by encounters with friends or neighbors who naturally enquire as to the nature of the walk. Such potential breaches of confidentiality may be of particular significance when the research engages with sensitive topics such as stigmatized health conditions. The somewhat novel nature of walking interviews may require researchers to be explicit in spelling out the advantages and key considerations of this method when complying with ethical approval processes that may be required of them.

6 Walking Interviews in Practice: Introducing Mrs. Brown and Mr. Mitchell

Walking is almost an ambulation of mind.

~ Gretel Ehrlich (Ehrlich 1992, p. 28)

This section explores some of the issues raised above through two illustrative case studies of walking interviews conducted with older adults. These walking interviews were conducted during fieldwork undertaken for qualitative health research exploring experiences of food security and insecurity among 21 older adults living in rural Tasmania, Australia (King 2014). The two older adults have been assigned pseudonyms to protect their anonymity.

6.1 Walking with Mrs. Brown

Mrs. Brown is a warm and talkative 77-year-old woman who was a dairy farmer for 45 years. Widowed 24 years ago, Mrs. Brown lives alone on her farm. She has several serious medical conditions including heart disease, spondylosis, and type 2 diabetes, and she now walks no further than her letterbox at the end of her short driveway. During the walking interview in her garden, Alexandra and Mrs. Brown walked a total distance of perhaps 20–30 meters over a period of 20 minutes, creating an open loop around three sides of her small home. This walk was characterized by a gentle pace and a stop-start rhythm, with Mrs. Brown stopping occasionally to rest or admire various flowers and plants in her garden.

Being outside with Mrs. Brown generated several useful visual prompts which were not available inside her home, and these provided a powerful means for

Mrs. Brown to talk further about her emotional attachment to her farm. She talked freely about both the immediate physical surroundings and our shared views of the landscape in the distance. At the beginning of the interview, she started by talking about the weeds in her garden but quite suddenly, and without prompting, she gestured at, and then described her enjoyment of, the soil and plants close by in her garden, as well as the surrounding paddocks and mountains. This walking interview also provided other visual prompts for talking about her past experiences and achievements. As a farmer and long-time resident, the work she and her husband did together on this farm was evident; for example, in the form of additional farming land they purchased and a dam they built together. The walking interview also provided visual evidence of the changes Mrs. Brown has experienced in her environment during her later life: from her garden, we could see the farm's homestead where she used to live before she retired from farming.

The following excerpts from the walking interview transcript reveal that Mrs. Brown spoke fluidly and volubly, and this talk was infused with expressions of her bodily sensations and her positive emotions about her rural home environment.

Mrs. Brown – It is funny, it has got a feeling that you can't actually explain. It's just a feeling of. . . I don't know if it is contentment or what it is. But you just look at them [the cows] and you marvel. Oh, gee, they are beautiful, aren't they? You know?

...

Mrs. Brown – Everything is being created all the time, and you see that. And you are growing with it, all the time. And I think you are blessed to be able to do it. Because. . . it doesn't matter what it is, it's all alive. You know what I mean? So, I think, when you walk on the farm, you can feel the life in it. Yeah, I take my shoes off and I walk around on this grass, and it is just like walking on a beautiful, soft carpet. You know? It is so lovely to walk on. . . Well, it is living.

...

Mrs. Brown – It's peaceful. It's very peaceful looking like that. As I say, if you are uptight or anything, and you walk out and you look across that, you feel at peace. You know what I mean, don't you? See, even here, a tractor in the distance. It has got that sort of feeling of – you *belong*. So, you know. . . and look at the mountains. It is just as if they are asleep. It is beautiful.

Mrs. Brown's talk reveals how her emotional, sensory, and aesthetic enjoyment of her rural environment adds meaning to her daily life in older age, even after she has retired from active farming. Primarily, her emotions about where she lives are characterized by feelings of peace, belonging, contentment and "blessedness." Thus, this walking interview revealed that the rural environment Mrs. Brown has lived in for almost 60 years continues to nourish and support her in old age.

6.2 Walking with Mr. Mitchell

Mr. Mitchell is an inquisitive and well-educated man who tells detailed, lengthy, and lively stories. He has farmed his family's land for over 50 years. Now aged 77, Mr. Mitchell has been widowed twice. He has three adult children and two teenage

children. He has had a heart attack and his hearing is low, but otherwise he is in good health and he is very physically active.

The walking interview with Mr. Mitchell was a quite different in character and content to the one conducted with Mrs. Brown. It took place over a distance of two kilometers, on a route which first went steeply uphill and then steeply downhill, over a period of about 45 minutes. This was primarily a goal-oriented walk for Mr. Mitchell. For the interview, he had chosen a walk on his farmland that he often takes; during it, he times how long it takes him to reach the top of a hill, which he then records in a notebook. Mr. Mitchell has been doing this timed walk for many years, and he sees it as a strategy for keeping his heart healthy and for loosening up his body, as well as providing a time-based benchmark for his overall well-being.

Mr. Mitchell and Alexandra set off at a rapid pace up a steep, rocky path which took us up a hill on his property. In contrast to our earlier in-depth interviews, it became clear that Mr. Mitchell was a little reluctant to talk much during this interview, as he was concentrating on keeping up his rapid walking pace. Answering questions very succinctly and without engaging in any extraneous speech, he walked up the hill without pausing, only stopping when we reached the predetermined half-way point of the walk: a tree at the top of the hill. The following excerpts from the interview transcript convey the succinct and unexpansive nature of the data generated.

Alexandra – “So, does this feel like home to you, this land?”

Mr. Mitchell – “Yeah. Yeah.”

Alexandra – “So, you like being outside?”

Mr. Mitchell – “Yeah.” [Silence while walking. Sound of interviewer unzipping her jacket. Heavy breathing of interviewer. Footsteps.]

...

Mr. Mitchell – [He stops at the top of the hill and looks at his watch.] “24 minutes. That is not very good. On Saturday I did it in 22 and a half.”

From the top of this hill, Mr. Mitchell pointed out the extent of his farmland, and once the timed aspect of the walk was complete, he became noticeably more talkative on the return journey. However, asking Mr. Mitchell questions was somewhat constrained by his fast pace; he was often several meters in front and could not always hear the questions being asked. Fortunately however, the digital recorder was capable of picking up his voice from this distance so most of the verbal data was recorded. On our downhill journey, Mr. Mitchell pointed out various physical landmarks and features in a primarily factual manner, apparently aiming to impart information rather than communicate feelings.

Mr. Mitchell – “There are quite interesting things to look at. In summer, there is the butterflies. That is kangaroo poo. That is wallaby. Echidna holes.”

...

Mr. Mitchell – “Yeah, I can tell you all the things as we go back down.”

...

Mr. Mitchell – “I actually like to do [this walk] earlier in the morning. Because if I am working for the rest of the day, I have loosened myself up so that I can get a lot more done.”

6.3 Reflections on the Case Studies

These two case studies illustrate the extent to which walking interviews can differ, both with regards to the experience itself and the mood of the data generated by the research encounter. However, these differences do not pose a challenge to the validity of walking interviews for explorations of how people experience particular places. Instead, these differences help to underline the specificity of each walking interview, which is heavily informed by the idiosyncratic characteristics and preferences of each individual who participates in the method. For example, these case studies illustrate that a walking interview was not capable of transmogrifying an action-oriented and analytically minded man, Mr. Mitchell, into a rhapsodic and emotional communicator about his relationship to his farm land. And during Mrs. Brown's sit-down interviews prior to the walking interview, she had already demonstrated a good capacity to articulate her emotions about her surrounds. Hence, the mood of the interview and the nature of the data generated reflect the unique personalities and life approaches of the respondents.

The value of these walking interviews lies in their ability, when used in addition to more sedentary methods such as in-depth interviews and ethnographic observation, to provide valuable insights into older adults' distinctly different engagements with rural places and their distinctly different strategies for healthy aging. Mr. Mitchell's walking interview was highly task-oriented in terms of his explicit aim to reach the top of a hill and achieve a specific time-related performance goal. This took primacy over the researcher's desire to make this a communicative encounter. When Mr. Mitchell did talk, it was often quite brief – in contrast to his more expansive conversation during his earlier in-depth interviews – and his talking was usually directed towards imparting knowledge about his land. Hence, one might reasonably conclude that Mr. Mitchell's engagement with his farmland is primarily motivated by intellectual curiosity and a desire to know what occurs there, as well as a desire to achieve specific health-related goals in that environment.

In contrast, Mrs. Brown's walking interview was primarily directed towards communicating with the researcher, as well as towards reveling in and expressing her positive emotions about her farmland. Mrs. Brown did not traverse much distance during the walking interview, as the slow pace was determined both by her low mobility and her desire to stop and quite literally "smell the roses" along the way. This walking interview, when considered in conjunction with her other in-depth interviews and ethnographic observations of her home, provided insights into Mrs. Brown's emotional responses to the land and her prioritizing sensory pleasure and comfort, over and above achieving perhaps more tangible outcomes, such as walking a long distance or living a long life.

While quite different in mood and content, these two walking interviews reveal a common capacity of the method to generate in-depth and in vivo data about people's engagement with place, and in this particular case, older adults' engagement with their rural environments. These case studies also allow further engagement with earlier questions about whether researchers can experience embodied empathy during walking interviews. In the first case study, the very low mobility of Mrs.

Brown was evident, which generated feelings of sympathy rather than empathy in the researcher; if anything, she felt more agile and more capable than she usually does, by comparison with Mrs. Brown. In the second case, the researcher felt quite distinctly physically different to the older adult, who was over 30 years' her senior: less sure of her footing, less confident she could reach the top of the hill, and less capable than he. Albeit for different reasons, neither of these walking interviews generated a sense of a shared bodily experience of aging or physical agility, but they did provide an invaluable opportunity to engage in in-depth qualitative research with participants in an empathic and flexible manner.

7 Conclusion and Future Directions

Walking is an activity which is simultaneously mundane and rich with meaning. Part of most people's everyday experience of life, walking can be either necessary or pleasurable, task-oriented, or experiential; but walking on two legs is always recognizable as a particularly human activity. Harnessing the dichotomous power of walking as both everyday and metaphorically rich, walking interviews are ideally suited for qualitative health research which seeks to engage with the nature and meaning of bodily experiences including physical well-being, illness, aging, or disability and to explore the ways in which these experiences are interwoven with the places in which people live and the meanings they have for their lives. Through physical movement and empathic social interaction, walking interviews help to generate "a deeper, experientially rich understanding" (Irving 2010, p. 26) of people's lives, their bodies, and their relationships to the places they inhabit, much of which lies in substrates of people's inner lives and hence is often inaccessible by quantitative health research methods.

Importantly, walking interviews also engage with the metaphorical meaning that walking holds for human lives (Kusenbach 2012). It is not merely a means of physically transporting ourselves; it carries a symbolic weight too, such that it can be seen to represent our life's journey. Hence, when "putting one foot in front of the other," one is not merely walking, but is also moving forward with life, sometimes in the face of hardship or pain. If life is indeed a long walk, then researchers can gain significant insights into people's lives by taking a short walk with them.

However, a balance needs to be struck between enthusiasm and caution in relation to walking interviews. While they hold considerable promise for researchers aiming to achieve physical closeness and gain insights into bodily experiences of place, walking methods are not necessarily superior to other, more traditional qualitative health research methods like sit-down interviews and ethnographic observation. Merriman (2014, p. 183) usefully advises researchers to avoid spurious claims that mobile methods are superior to traditional methods and to focus instead on "adopting modest, 'weak', open, non-representational epistemologies and ontologies – not as a means to grasp and represent elusive practices, but as a means to experiment and *move with*."

While they are open and modest in their intent, walking interviews do provide valuable opportunities for researchers to move with participants, engaging in collaborative dialogue while shoulder-to-shoulder, thereby facilitating rapport, empathy, and in situ insights into human experiences. Although social and cultural geographers have increasingly employed walking interviews in recent years, considerable potential remains for health researchers to do likewise. That is, for them to employ walking interviews either alone or in combination with other methods, whether in rural environments, urban streetscapes, or healthcare settings such as hospitals, in order to uncover and explore human beings' intangible, nuanced and meaningful experiences of illness, wellness, or healthcare.

A possible future direction for mobilities research lies in one of the criticisms it receives. In drawing attention to the rich potential of walking interviews for qualitative health research, we might run the risk of generating "an over-animated mobile subject", in which movement and action are, perhaps inadvertently, elevated above other human experiences of stillness, waiting, or immobility (Merriman 2014, p. 167). Particularly with respect to human experiences of illness, disability, and aging, such stationary states of "being" also carry significant experiential and metaphorical weight and, as such, are also worthy of close and empathic enquiry. So as to deepen understandings of experiences of health and illness, researchers might fruitfully illuminate the nature of human experiences of being immobile in a highly mobile world, by developing innovative research methods which engage with waiting, sitting, and even lying down.

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Participant-Guided Mobile Methods

73

Karen Block, Lisa Gibbs, and Colin MacDougall

Contents

1	Introduction	1292
2	Power and Control	1293
2.1	Informal Play Areas: The Creek	1295
2.2	Informal Play Areas: Vacant Land	1295
3	Spatially Situated Research	1295
4	Eliciting Different Data While Mobile	1297
5	Some Additional Risks to Consider with Mobility!	1298
6	Generating Rich, Contextually Informed Data from Diverse Participants	1298
7	Mobile Methods Enabling Complex Insights	1299
8	Participant-Guided Mobile Methods: Limitations and Challenges	1300
9	Conclusion and Future Directions	1301
	References	1301

Abstract

Health research is increasingly concerned with tackling health inequalities and inequities. Given that poorer health outcomes are often experienced by those who are suffering a degree of socially, economically, or environmentally determined disadvantage, it is incumbent on us as researchers to include the views and voices of diverse and sometimes marginalized or vulnerable population groups. Challenges which may accompany this imperative include engaging so-called hard-to-reach populations, and addressing an imbalance of power that often occurs between researcher and participant. Participant-guided mobile methods

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are one strategy for rebalancing this power differential when undertaking qualitative research. In this chapter, we describe the method and several case study examples where the authors have used it. We also discuss the types of research questions for which it is particularly well-suited along with its benefits and its challenges. When compared with a more traditional face-to-face interview, participant-guided mobile methods allow participants more power and control over the interview process. In addition, the method can yield observational and visual data as well as interview data, and is useful for including children and other participants who may be less articulate or lack proficiency in the language of the interviewer as it provides opportunities to “show” as well as “tell.”

Keywords

Mobile interviews · Qualitative · Place · Space · Neighborhood · Walking interviews · Power

1 Introduction

Participant-guided mobile methods combine a participant-led guided tour with in-depth interviewing. The tour can take place on foot or using a vehicle and can even be virtual, investigating participants’ online worlds or using technologies such as Google Earth or Google Maps to explore otherwise less accessible places. Combinations of walking and talking, sometimes described as “go along interviews,” while still relatively uncommon in health research, have been used within a number of social science disciplines to investigate interactions between people and their social and physical environments (see, for example, Carpiano 2009; Kusenbach 2003; see also ► Chap. 72, “Walking Interviews”). The route for such walking interviews can potentially be determined to a greater or lesser extent by either the interviewer or the interviewee (Evans and Jones 2011). Our preferred term – participant-guided mobile methods – emphasizes a number of important attributes: the value of participants choosing the route, that interview data are only one of the multiple types of data that can be collected with this approach, and the fact that this is not a single method but rather a flexible set of methods that share particular characteristics. We discuss these attributes in more detail below.

The approach is best characterized as a type of *rapid ethnography*, which typically draws on a variety of data sources “to understand the social meanings and activities of people in a given ‘field’” (Brewer 2000, p. 11). As with participant observation (but without the extended time commitment that method often entails), mobile methods provide an opportunity for researchers to gather multiple types of data simultaneously, adding contextual, observational, and potentially also visual data to interviews conducted in a naturalistic setting. There is, however, a critical difference between participant observation and participant-guided methods in the degree to which it is the participant or participants who decide what the researcher is shown and to what they should attend.

This characteristic of the method – the comparatively greater degree of control apportioned to participants – provides several advantages (and some challenges). In this chapter, we will discuss some of these methods’ key features: a rebalancing of power and control between participants and researchers, recognition that people’s lives are conducted in space, and the capacity of the method to yield rich, contextually informed data from a diverse range of participants. The discussion will draw on several case study examples where we have used this approach.

2 Power and Control

Health research is increasingly concerned with tackling health inequalities and inequities. Given that poorer health outcomes are experienced predictably along a gradient of socially, economically, or environmentally determined disadvantage, it is incumbent on researchers to include the views and voices of diverse and sometimes marginalized or vulnerable population groups. Challenges which may accompany this imperative include engaging so-called hard-to-reach populations, and addressing an imbalance of power that often occurs between researcher and participant. While research methods *per se* cannot reverse material, political, and social distances associated with different class and educational backgrounds, participant-guided mobile methods are one strategy for rebalancing some of the manifestations of these power differentials when undertaking qualitative data collection.

Bourdieu (1996, p. 19) has argued that researchers need to practice reflexivity along with “active and methodical” listening to avoid perpetrating “symbolic violence” on research participants who are frequently “disempowered” in the research process. He expands on this idea as follows:

It is the investigator who starts the game and who sets up its rules: it is most often she who, unilaterally and without any preliminary negotiations, assigns to the interview its objectives and uses, and on occasion these may be poorly specified – at least for the respondent. This asymmetry is underlined by a social asymmetry which occurs every time the investigator occupies a higher place in the social hierarchy. . . .

Thus, if we wish to avoid inflicting such real – albeit intangible – harms on our participants, it is incumbent on the researcher to seek to redress this asymmetry in power as far as possible. Qualitative research paradigms have developed, in part, from researchers’ discomfort with power dynamics in research and have been positioned by Denzin and Lincoln (2008) as democratically revolutionary. They take as a starting point the notion that research should be conducted *with participants* rather than *on research subjects*. Participatory methodologies take this idea further, seeking to engage participants throughout the research process including in conceptualizing the research problem or question, collecting and analyzing the data, and disseminating the findings (Cacari-Stone et al. 2014; International Collaboration for Participatory Health Research (ICPHR) 2013). It has been argued, however, that

such practices do not automatically disrupt the power gradient between academic institutions and the communities they study (Janes 2016).

Qualitative and participatory approaches are influenced by feminist methodologies that “emphasize non-hierarchical interactions, understanding and mutual learning” with particular attention paid to the way in which data collection methods may reflect unequal power relations (Sultana 2007, p. 375). Participant-guided mobile methods sit within this broad family of qualitative participatory practices and, we would suggest, can reduce the power differences between researchers and researched. Inviting participants to take one on a guided tour of their community or environment, generally with a broad stated purpose associated with the research topic, explicitly casts them as the experts, with the researcher in the position of guest in their territory. Participants plan and control the route and point out features of importance. The interview and tour take place simultaneously, with prompts varying according to what the participant is showing the researchers. Along with observational and recorded interview data, visual data such as photographs or maps (produced manually or with digital technology) can also be generated. With participants “shaping the direction (both literally and metaphorically) of the interview” a “more democratic (co)construction of knowledge” is thus facilitated (Holton and Riley 2014, p. 60).

The case study below, *Mobile Me*, presents two themes from a study using mobile methods with Australian metropolitan children, focusing on their accounts of what assists or impedes their mobility when they are not in the direct care and supervision of their parents. The control that participating children were able to exercise during the data collection process was fitting, given the concerns driving the research, which were about understanding how and why adults ration children’s independence in everyday life.

Mobile Me

Children’s independent mobility – considered important for promoting health and well-being – refers to the freedom to travel or move about neighborhoods without adult supervision (Nansen et al. 2015). It has been argued that in recent times, we have been facing a moral panic, driving an unnecessary preoccupation with taking the risk out of childhood (Gill 2007), and research has found that parents determine boundaries for their children partly in response to fears about potentially dangerous people (MacDougall et al. 2009).

This study was conducted in the northern suburbs of Adelaide, the capital city of South Australia. Four boys and six girls aged 8–14 were recruited from a government primary school that had participated in a broader study (MacDougall et al. 2009). We chose to travel by minibus, rather than use walking tours, because of the distance between the places that children wanted us to see, and the fact that we wanted to explore places that were potentially unsafe. We conducted separate tours for boys and girls because, in earlier research using focus groups, we had observed boys talking over the girls. We recognized children as active social agents by asking them to plan the route for the bus driver, based on places that they considered important. They drew the route on an enlarged extract from a local street map.

During the bus tours, the children were interviewed at places that they had nominated. Children also took photographs or suggested photo opportunities to the researchers. Two of the themes are described below.

2.1 Informal Play Areas: The Creek

Boys and girls of all ages described to us a local creek that they saw as important. In Australia, a creek usually connotes a river or stream in rural areas. When the children directed the minibus tour to this creek, however, it was apparent they had a different meaning. To the eyes of the adult researchers on the minibus, it was a concrete drain on the side of a busy road with houses backing onto one side and open farmland on the other. The children, however, directed us to trees in which they had constructed cubby houses. They showed us the bushes where they played “chasey” and ran around. A 10-year-old boy responded to a question of why he likes coming here by saying that “it’s like a big area and my backyard is not big enough to play chasey in.” They showed us ladders which had been placed over the fences of gardens of houses which backed on to the creek, allowing children easy access to the creek. Another 10-year-old boy said “it’s pretty much like my backyard” and added “last time I came here I spent probably about four hours here.” Children of all ages reported that sometimes their parents allowed them to go there by themselves to meet other children. Motorbikes were driven by young adults off the road on a track next to the creek, and some children said this stopped their parents from allowing them to go there without their supervision. The 10-year-old who described the motorbikes was asked “who decides whether you can play here by yourself or not?” He answered that it was mum, and the interviewer asked “do you think that’s fair that you can sometimes but not other times?” He replied “yes it is fair.”

2.2 Informal Play Areas: Vacant Land

The younger boys directed the minibus tour to small patches of vacant land which were odd shaped, smaller than a house block, and with bushes and trees. There was enough open space here for them to come with their friends and play improvised games such as football and cricket. These were not formal parks, but smaller areas maintained by the local government that were very important for these children because they were local. They did not have to cross busy roads to get there and their parents felt that it was safe enough to allow them to go there with friends.

3 Spatially Situated Research

As is evident from the case study described above, participant-guided mobile methods also acknowledge that people’s lives take place in spaces and involve travel. The health impacts of place, both direct and indirect – through its influence

on social contexts and health-related behaviors – are well recognized. Scholars have argued that in order to gain a deeper understanding of place-based determinants of health, researchers need to engage explicitly with the “spatiality of social life” and peoples’ experiences of their social and physical environments (Rainham et al. 2010, p. 668; Finlay and Bowman 2016).

To this end, quantitative researchers have begun utilizing technologies such as GIS (Geographical Information System) and GPS (Global Positioning System) to track people’s movements and interactions with the spaces in which they live (Rainham et al. 2010). Qualitative inquiries are also complementing these studies and providing a deeper understanding of the meaning of these interactions. Participant-guided mobile methods are particularly suited to studies concerned with people’s relationships with their communities and their environments and to studies concerned with how people interact and are influenced by their space and place. These qualitative methods also obviate some of the ethical and privacy dilemmas associated with tracking technologies, which some participants might regard as constituting excessive and unwanted surveillance.

Mobile methods are also aligned with the “new mobilities paradigm” in social research, the proponents of which argue that social science has historically ignored people’s systematic movements and corresponding continuous reconfigurations of networks of people, objects, and environments as foci of study (Sheller and Urry 2006). Underlying this paradigm are understandings of the embodiment of human experience in space and time, and of a fundamental difference between being in motion and being static, “both in terms of the kinds of engagement with the world that it prompts, and the kinds of knowledge and identities that it therefore engenders” (Hein et al. 2008, p. 1268). The mobilities paradigm emphasizes that all places are tied into at least thin networks of connections that stretch beyond each such place and mean that nowhere can be an island. It begins from the complex patterning of people’s varied and changing social activities, which mean that travel is necessary for social life and connections. It examines the proliferation of places, technologies, and gates that enhance the mobilities of some while reinforcing the immobilities of others. A corresponding mobilized ethnography involves walking or traveling with people as a form of deep engagement in their worldview (Sheller and Urry 2006; see also ► Chap. 72, “Walking Interviews”).

Studies using mobile methods have also demonstrated that there is a relationship between what people talk about and the places in which they are talking. Geographers Evans and Jones (2011) compared discourses produced in sedentary and walking interviews in the Rescue Geography project exploring peoples’ personal connections to their area. They found that participants in the walking interviews focused more on environmental features while the sedentary interviews produced more narratives about people. Thus, mobile methods are most appropriate when place is a significant part of the research question and less so if researchers are primarily interested in people or narratives located remotely.

Participant-guided mobile methods are clearly suited to engaging with people's spatially situated and mobile experiences. In the case study below, *Beyond Bushfires: Community, Resilience, and Recovery*, participant-guided mobile methods were used as one part of a larger mixed-methods investigation into the medium- to longer-term impacts of the "Black Saturday" bushfires, which devastated many communities across the State of Victoria, Australia, in February 2009. The research was focused on the interaction between individual and community trajectories in the years following the fires.

Beyond Bushfires: Community, Resilience, and Recovery

The Black Saturday bushfires were responsible for the loss of 173 lives, the destruction of 3500 buildings including 2133 homes and profound and prolonged social disruption in many affected rural communities. For this large mixed-methods study (Gibbs et al. 2013), approximately 1000 people completed surveys 3–4 years after the fires and again 2 years later, and 35 participants from severely affected communities also took part in a qualitative study using participant-guided mobile methods. Participants ranged in age from 4 to 66 years of age and included two grandparents, 17 parents, five children, and two young adults who were teenagers at the time of the fires. Some chose to take part with family members, as a couple or parent with a child for example.

These participants were invited to take us on a guided tour of places in their community that were important to them, with questions focusing on why these places were significant. At the participant's discretion, some tours were conducted entirely on foot while others included a driving tour to explore more distant parts of the community. We took photographs of the significant places and objects, as indicated by the participants, during the tours, and the photographs served as additional data for analysis as well a useful way to illustrate the project. Given the potential to evoke past traumas, we did not ask participants directly about their fire experiences. Most, however, chose to describe those experiences in some detail and these stories were certainly rendered more vivid for the researchers by being told in situ.

4 Eliciting Different Data While Mobile

Perhaps because the participants felt like hosts – and because of the relevance of their houses, either surviving or rebuilt – in most cases, we were invited into people's homes as well as being taken on a tour. This meant that many of the interviews took place in two phases, beginning or ending with a (sometimes quite lengthy) additional sedentary interview over a cup of tea. When the interview data were analyzed, it was apparent that the topic of conversation almost invariably changed when the interview switched from sedentary to mobile (or vice-versa). In many cases, the sitting interview elicited more personal information and stories while the mobile phase tended to focus more on the broader community and the environment (Block et al. 2014).

5 Some Additional Risks to Consider with Mobility!

As already noted, our participants for this study included children and, in one case, a very articulate and independent 7-year-old boy was permitted to take us on a tour of his small town without a parent. He confidently took charge of the tour, instructing us as to which things we should and should not photograph on the way. At one point, however, our attempts to address the natural power imbalance between adults and children appeared to have been too successful. We were impelled to wrest back some of the control we had relinquished when he suddenly dashed across the main road, apparently without looking for cars, and we had to exert considerable authority to convince him that he should not do so again (Block et al. 2014).

6 Generating Rich, Contextually Informed Data from Diverse Participants

As noted earlier, participant-guided mobile methods comprise a flexible range of techniques that are useful for conducting research with a broad range of participants. The multiple simultaneously produced forms of data that are generated – observational, visual, and interview data – can be integrated and synthesized to build a rich and contextually informed understanding of people’s lives in the spaces in which they are lived. These methods allow the researcher both to experience participants’ environments themselves and to interrogate people’s perceptions, interpretations, and navigations of those environments – providing a range of insights not generally accessed through (sit-down) interviews alone (Carpiano 2009). Concerning this last point, Evans and Jones (2011, p. 850) differentiate between walking (or cycling) interviews, whereby researcher and participant are exposed to the “multi-sensory stimulation of the local environment” and interviews that take place in a car or a train, for example, which are “essentially sedentary from [a] bodily perspective” although undertaken while in motion.

Many of the more common research techniques, such as interviews, focus groups, and surveys, are ideally suited for gathering data from relatively well-educated participants with opinions on topics that can be readily articulated. By way of contrast, participant-guided mobile methods, similarly to other innovative methods using photography or drawings (for example), can be used effectively to include participants who may be less articulate and can consequently be marginalized or disregarded in much research. As well as using these methods successfully with children (as in the case studies described here), we have also used them with recently arrived migrants, not yet fluent in the language of the researchers. The approach provides opportunities to *show* as well as *tell* and more readily accommodates nonverbal cues, pauses, and silences than a traditional interview.

Mobile methods can also be used to understand how places are diversely experienced, by comparing, for example, the way spaces are experienced and negotiated

by different genders and races or by able bodied and empowered individuals compared with those with disabilities, the aged or the young (Finlay and Bowman 2016).

The third case study, *Stepping Out*, is described below and investigated how children negotiate their independent travel. The use of participant-guided mobile methods elicited more complexity and interdependency of contributing elements to those negotiations than was revealed by the other methods used in the study.

Stepping Out: Children Negotiating Independent Travel

This study, conducted in 2011–2012 in the inner northern suburbs of Melbourne, Australia, aimed to explore the role that children played in negotiating their own active and independent travel. Participants were children aged 10–12 transitioning from primary to secondary school, a time when children often begin to undertake travel – especially to school – that is less supervised by adults. The multimethods study included observation, focus group discussions, and interviews as well as participant-guided mobile methods. A small number of parents and teachers also took part in interviews to provide additional contextual information.

In keeping with principles of participatory research and a child-rights informed practice, a small group of child participants were recruited as research partners in the early stages of the study to inform subsequent stages. Without prompting, the group suggested we should go outside and trace the actual routes taken by children. Following one of these mobile methods journeys, a recommendation was made that researchers should accompany children on travel journeys using the same mode of transportation as participants, such as a bike. Consequently, ten participating children took us on a routine travel journey – in most cases to school but also in some cases to shops and parks – to demonstrate the way in which they usually traveled to that destination (Gibbs et al. 2012).

7 Mobile Methods Enabling Complex Insights

A striking consequence of using participant-guided mobile methods in this study was that it enabled us to identify a considerably greater degree of complexity in children's independent mobility than was articulated through the focus group discussion. We found, for example, that when children told us they walked to school with their parents or with younger siblings, they did not necessarily walk side by side, but instead, they were often spread out along the route, perhaps regrouping at intersections to ensure safe crossing. We found that children's mobility was negotiated through multiple features of people, events, and environments. It was characterized by gradual transitions, use of technology such as mobile phones, significant influence of travel companions including friends and relatives, and the use of passive surveillance by parents on visible routes (Nansen et al. 2015).

8 Participant-Guided Mobile Methods: Limitations and Challenges

This chapter has demonstrated that participant-guided mobile methods provide a valuable addition to the qualitative researcher's array of methods. Here, we discuss some limitations. Firstly, as already noted, these methods are useful when place is salient to the research question. If researchers are seeking to explore conceptual narratives unrelated to place, sedentary approaches may be more productive (Evans and Jones 2011). As always, when undertaking research, reflexivity on the part of the researcher is recommended. While a search for greater authenticity may underpin researchers' motivations for undertaking interviews in a naturalistic setting that is familiar to participants, we should still be aware that research encounters invariably comprise an element of performance where the participant and researcher are coconstructing a narrative and identity. A participant-guided tour is no exception to this rule, and the onus is on the researcher to reflect on their role as well as the role of their chosen method in coconstructing knowledge (Holton and Riley 2014).

There are also a number of additional challenges associated with this approach compared with a sedentary method. Weather – either very hot, very cold, or wet – may limit its feasibility and/or willingness of participants to undertake a guided tour. Both researchers and participants need to maintain a degree of flexibility in order to adapt to inclemency as well as other local conditions. As also noted previously, participant-guided mobile methods may be suitable for investigating the way in which participants with a disability or otherwise limited mobility navigate their environments. Any limitations to mobility, however, obviously need to be thought through when planning how to conduct the research. Limitations to mobility may occur because of personal characteristics of the participant or because the places under consideration are inaccessible. In one case, we were conducting research with recently arrived refugee background youth who were able to use Google Earth to show us places they had lived before coming to Australia.

In order to maximize the value of collecting data that is spatially situated, researchers will need to consider how they will include locational identifiers that can be linked to the generated narrative. These could include photographs, notes, maps, or conversational prompts that take note of local environmental features (Carpiano 2009; Evans and Jones 2011; Finlay and Bowman 2016). Researchers also need to plan how they are going to manage technical issues associated with recording the interview. While we have had success using a high-quality digital recorder held by the researcher, ambient noise and/or multiple participants may compromise the sound quality. Having more than one recording device and asking participants to hold one as well may help overcome this problem but clearly adds to the subsequent labor required when transcribing.

Finally, while empowering the participant has positive ethical implications, these methods also raise some ethical complexities. Safety is of course a primary consideration and various combinations of terrain and participant attributes may raise concerns as demonstrated in the *Beyond Bushfires* case study described above. Similarly, in the *Stepping Out* study, researchers had to take care that they did not

divert the child participants from attending to traffic and other hazards. If the tour is undertaken while driving, then clearly driving skill of either the participant or researcher is relevant as are distractions associated with the research process. Confidentiality is also potentially more difficult to manage when using these methods – particularly if the tour is taking place in an environment where the participant is likely to be recognized and the researchers are conspicuously unfamiliar.

9 Conclusion and Future Directions

In this chapter, we have discussed some key features of participant-guided mobile methods along with some of their limitations and challenges. When undertaking research where space and/or movement are relevant to the research questions they provide a valuable addition to the researcher's cache of methods. They can be combined with other qualitative or quantitative methods and generate rich and contextually informed data that can help us to understand the ways in which place shapes and interacts with people's experiences. In such cases, these methods pass the methodological test, that increasing the number of data collection methods used is justified if they provide additional and complementary information (Darbyshire et al. 2005). They are particularly useful for including the contributions of participants who may be less articulate and can help to shift the balance of power between researcher and participant towards the participant in those cases. This feature makes them of particular use for health researchers seeking to investigate health inequalities and inequities affecting marginalized or vulnerable population groups.

In future research, we expect that using participant-guided mobile methods will assist researchers to extend their investigations of social determinants of health to incorporate more explicitly environmental, place-based, and mobility-associated determinants as well. Given the flexibility of these methods, the potential for researchers to incorporate new technologies and adapt them to new research questions in creative ways we have not yet imagined is considerable.

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Digital Storytelling Method

74

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Contents

1	Introduction: What is Digital Storytelling?	1304
2	Defining Digital Storytelling: A “Codified” Process	1305
3	Producing Digital Stories: A Workshop-Based Practice	1306
4	Initiating Critical Dialogue About DST as a Research Method in Health and Social Science Research	1307
4.1	Producing “Voice”	1309
4.2	Sharing Digital Stories	1312
5	Sharing the Stories: The Digital Afterlife	1314
6	Conclusion and Future Directions	1316
	References	1318

Abstract

Digital stories are short (2–3 min) videos using first-person voice-over narration synthesized with visual images created in situ or sourced from the storyteller’s personal archive. Digital storytelling (DST) is a codified process, originating in the 1990s as part of a community development arts initiative to mobilize voices marginalized by dominant, institutionalized media. Rooted in the rapid emergence of arts-based health research, DST is used in health promotion research and practice, public health and community-based participatory research, and multi-disciplinary fields such as psychiatry, disability studies, and social work, covering

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a range of physical, mental, emotional, and spiritual health topics and perspectives. In this chapter, we describe a case study in children's mental health, which combined DST and traditional ethnographic and participatory analysis methods. Exemplars from the case study are used to initiate critical dialogue about DST, inspired by key methodological questions raised by education, cultural, and media scholars, but generally lacking in health and social science scholarship. We consider how multiple human and institutional actors negotiate and shape the story told and the extent to which narrative constraints imposed by DST problematize claims around "voice" and representation. We conclude with thinking about the "after life" of digital stories, including how singular narratives can connect the personal and the structural to effect real social change.

Keywords

Digital storytelling · Arts-based health research · Participatory analysis · Qualitative research · Youth · Voice

1 Introduction: What is Digital Storytelling?

Digital storytelling (DST) is an intensive, workshop-based practice to guide the production of short audio-visual vignettes, or digital stories, using a structured process (Vivienne 2011). Digital stories are 2–3 min in length. They combine first-person voice-over narration, based on an individual's story script, with music, video clips, digital photographs, text, and drawings, sourced from the storyteller's personal archive or produced in situ. Digital tools (personal computers, digital cameras, editing software) are used to produce the digital story, and digital media (DVD's and/or the Internet) are used to mobilize and distribute the story (Vivienne and Burgess 2013). The "story" is positioned as a highly personal and authentic autobiographic account of the lives of ordinary, often marginalized individuals, and characterized as "tales told from the heart" (Meadows cited in Rossiter and Garcia 2010, p. 37).

Rooted in the rapid emergence of arts-based health research (see for example, Boydell et al. 2012), DST is emerging as a research method alongside innovations in more traditional qualitative and participatory research approaches and in different health research contexts, such as public health (see for example, Gubrium et al. 2013). The growing interest in digital storytelling likely coincides with claims that arts-based health research enhances researchers' understanding of participants' "lived experiences," empowers and engages participants in new ways, addressing or rebalancing power relations, accounts for emerging skills and abilities, including the growth of visual literacy, particularly among vulnerable populations, and helps to initiate social change by creating a platform for dialogue about troubling health topics (Boydell et al. 2012; see also ► Chap. 64, "Creative Insight Method Through Arts-Based Research").

DST is taken up in a number of ways, as a practice in professional clinical education, and as a research method (Wyatt and Hauenstein 2008; Gubrium 2009; Fenton 2013). It is used in nursing research (Stacey and Hardy 2011) and disability studies (Rice et al. 2015), studies on mental health and psychiatric practices (Baker

et al. 2015), and as a knowledge translation tool (Ferrari et al. 2015). As a research method, DST has focused on gender and health from a feminist perspective (see for example, Gubrium et al. 2011) and also on the purported health effects of participation in the digital storytelling process (Gubrium et al. 2016).

A variety of health topics have been studied using DST as a research method. See for example, research about the experiences of individuals across the life course living with chronic and acute illnesses such as HIV/AIDS (Willis et al. 2014), dementia (Stenhouse et al. 2013), and psychosis (Boydell et al. 2016) or with difficult transitions from nursing trainee to professional practice (Stacey and Hardy 2011). The therapeutic or health-promoting attributes of participating in DST are reported, including individuals' recognition of their strengths and resilience in spite of difficult circumstances (Willis et al. 2014), enhanced understanding of and ownership over life experiences and how they are told (Ferrari et al. 2015; Gubrium et al. 2016), and improved self-confidence and socially supportive connections (Stenhouse et al. 2013; Gubrium et al. 2016). Despite the growing popularity of digital storytelling as a research method, it is relatively new to health studies (Lal et al. 2015). The DST process and the digital story as a product, are mostly unexplored but inter-related topics (Rossiter and Garcia 2010), and key methodological questions raised by education, cultural, and media scholars (Alrutz 2013; Worcester 2012), are generally lacking in health and social science scholarship.

2 Defining Digital Storytelling: A "Codified" Process

It is difficult to reach consensus on a definition of DST because as an emerging method of communication, it is being used in the midst of an ever-changing landscape of digital production (Wales 2012). For this reason, we define digital storytelling in relation to a codified process used to produce stories, originating in the 1990s, as part of a community development arts initiative to mobilize "ordinary" people's voices considered marginalized by dominant institutionalized media (Worcester 2012). The Centre for Digital Storytelling (CDS) in Berkeley California developed the codified process underpinning the DST model in its "classic" form (Burgess et al. 2010) and this is generally considered to be a preeminent model in amateur digital video composition (Fulwiller and Middleton 2012). The DST codified process is designed to help individuals produce, rather than simply consume media stories, democratizing the process of media production as people learn to tell their own stories (Alrutz 2013). Expert power is subverted in this process as individual, "ordinary" stories are purported to represent a more amplified and "truthful" voice, which can then be directed toward initiating social change (Worcester 2012).

The production of a "good" story is essential to the objective of DST in order to link the individual, personal narrative to the socio-political sphere. An esthetically appealing story is likely to maximize its relevance by having a greater impact on audiences. Poletti (2011) refers to this goal as "coaxing" for a good story. Gubrium (2009) raises a similar point, describing digital stories as "shaped" by instructional standards on how to tell a compelling story, which are known as the seven elements of

Table 1 The seven elements of digital storytelling

1. Point of view	What do you want to say?
2. Dramatic question (story structure)	How can you say it best?
3. Emotional content	Helping your audience care.
4. Voice	Only you can tell your story.
5. Soundtrack	Add music and other auditory elements for impact.
6. Economy	Keep it simple when it comes to words & images.
7. Pacing	Give viewers time to take in the story.

DST, a hallmark of the California model (see Table 1). The purpose of the seven story elements is to ensure that novice storytellers will be able to create a successful story because the narrative will “satisfy, surprise and engage the viewer” (Poletti, p.78).

The power of the digital story lies in its first person narrative, the story as written and “voiced” by the participant who tells their own story. Initially, priority is given to story content and how it is expressed rather than other audiovisual material (Worcester 2012). Script writing is foundational for the process of DST and the seven elements teach participants how to write a focused story, containing a point of view or dramatic question and emotional content, alongside participant-generated voice-over narration. The digital story may include an additional soundtrack. All of this must be accomplished economically, using a brief storytelling format that is paced to engage the audience.

The first step in the codified process involves choosing a particular moment from a larger story that could be told, and this choice is the basis for story content. This decision creates space for a resolution of some kind in response to a position or point of view the storyteller has taken. This choice must be articulated through a strong story structure that engages an audience by learning “how to say it best” (see Table 1). The concept of “voice” in DST is literal (the voice-over narration) but also metaphorical; the story is invested with emotion that can speak to and engage the listener, by personalizing the story. “Voicing a story” is the means by which audiences identify with the storyteller and the story is supposed to foster empathy and resonate with the listener. Economy and pacing refer to how the multimedia story is managed through editing to create a particular effect. Economy references the narrative’s potential to produce closure in a short amount of time by generating implicit meanings through symbolism and metaphor that link back to the storyteller’s point of view. Pacing governs how stories are structured to allow viewers to contemplate and potentially project themselves into the story.

3 Producing Digital Stories: A Workshop-Based Practice

DST is a workshop-based practice, which sets it apart from other methods for generating visual images (Vivienne 2011). Stories are produced during interactive group sessions with a small number of participants (typically 5–10), facilitated by professional digital storytellers over a three- to four-day period. This concentrated time is important for participants to experience full immersion in the workshop experience

(Gubrium 2009). The process follows a sequence of steps beginning with an overview of digital storytelling and a screening of exemplars from other DST projects.

The story circle is an important first step; participants share stories and receive feedback in a space that is meant to be comfortable and safe. The story circle builds individual and group confidence in learning how to tell and listen to stories at the same time that it provides mutual mentoring and fosters group cohesion and inter-connection (Vivienne 2011). DST workshops, and the story circle, have been compared to Paulo Freire's educational process of building critical consciousness (Freire 1970, cited in Gubrium et al. 2013) because it opens up reflexive space for participants to think analytically about the place their stories have in the world. Engaging in a collaborative group process of shared media production actively constructs individual and collective agency, as participants consider how their own stories represent individual experiences brought together to speak back to social structures of power (Vivienne 2011; Worcester 2012; Gubrium et al. 2013)

An individual script writing exercise (using the seven story elements) and the creation of a visual storyboard to accompany the text follows the story circle. Several drafts of the script might be produced, which is highly dependent on the individual participant's skills and desire to revise the story. Participants take photos, shoot video, or record audio segments as part of the workshop, and they may produce drawings in situ or bring material from their personal archive to edit into their digital stories. The technical aspects of DST come into play as participants record voice-over narration and learn how to use computer software to design, edit, and assemble their stories. The workshop typically concludes with a celebratory screening of the digital stories to all in attendance (Wilcox et al. 2012).

4 Initiating Critical Dialogue About DST as a Research Method in Health and Social Science Research

This section introduces a case study in youth mental health research, which combined DST and traditional ethnographic and participatory analysis methods. Exemplars from the case study are used to initiate critical dialogue about DST, inspired by methodological questions raised in educational, cultural, and media scholarship (Poletti 2011; Worcester 2012) but generally lacking in the health and social sciences. A central tenet of DST is that it democratizes media production by facilitating the creation of mediatized stories by "ordinary" people about their own lives (Alrutz 2013). With the proliferation of digital storytelling projects in a range of institutional contexts, how DST is understood and used may be appropriated by the attending institution, and constrained by the seven story elements and the workshop-based practice. All of which may be combined to shape the DST process such that the final product is considered co-created, and sometimes predictable in form (Burgess 2006; Worcester 2012).

Our project examined help-seeking narratives created by young people using DST as a participatory research approach to foster critical reflection and facilitate expression and communication about (often sensitive) aspects of their experience. Young people were asked to focus the substantive content of their stories on how

they manage everyday life when a parent has a mental health problem or diagnosed illness. This is a significant public health issue worldwide (Reupert et al. 2015), and while (under) estimates suggest that 12.1% of all Canadian children *under 12* have a mentally ill parent (Bassani et al. 2009), in this complex and under-serviced area little is known about how young people cope with the challenges they encounter and respond to services they receive, or how they would like to be supported in this context. A second objective of the study was to examine how young people acquire further competencies and skills through guided participation and active engagement in the research process, by documenting the process of arts-based knowledge production and dissemination.

Participants: Ten young people (13–19 years.; six females and four males) currently receiving community-based mental health services and self-identifying as having a parent with a mental illness participated in the project. Our sampling strategy was purposive (Patton 2015), to ensure variation among participant ages, gender, parental psychiatric diagnoses, and the type and length of young people's involvement with mental health services, including a range of referral pathways that could reflect different help-seeking experiences. Young people in the study were referred for help from school and hospital staff, a homeless shelter for youth, a children's crisis phone line and by family members, including in one case, the parent with mental health difficulties. Most ($n = 7$) lived at home with their parent(s), or other family members, and the remaining ($n = 2$) resided in residential group homes and one young person lived in supported housing on their own. Participants reported their parents experiencing a variety of mental health challenges including depression, bi-polar disorder, schizophrenia, psychosis, anxiety, personality disorder, and posttraumatic stress disorder.

Study Design: Participants worked together as a group, longitudinally over the course of the study, guided by adult facilitators to clarify study objectives and research questions (Project Introduction); produce 3–5 min digital stories (DST Workshop); analyze study data; provide feedback on project findings; and recommend knowledge translation strategies to reach and engage particular audiences (Analytic and End-of-Project Discussions) (see Fig. 1). Explicitly engaging young people in participatory analysis is a novel approach to DST and a significant but missing dimension of participatory research with young people generally (Nind 2011). Participant observation and informal interviewing methods enabled documentation of project activities and participant engagement in the research process.

Ethical Considerations: Prior to obtaining informed consent, the project manager (ES) met separately and at length with each potential participant to ensure they understood the study objectives, and the implications for participation, according to the research design. Mindful that participants could feel differently about sharing stories upon completion (Dush 2012), a two-stage consent process was incorporated. During the second stage, participants were asked to consider the extent to which they were willing to share their stories (the broadest possible choice being the Internet). This second consent process occurred during the end-of-project discussion (Fig. 1) and four participants chose to share their stories broadly. Recognizing that DST participants sometimes choose to tell painful stories, it was important to consider whether the process would be “triggering” for young people (Gubrium et al. 2013). We worked closely with the clinicians involved



Fig. 1 The study design

in recruitment to minimize the risk of harm and in our face-to-face meetings prior to obtaining consent to screen young people and carefully explain the potential risks of participating in the study, although we acknowledge that it is not always possible to gauge how participants will be affected. All young people were connected to a clinician they received support from and were encouraged to contact this person if they experienced distress during the course of the study, or afterwards.

The case example is presented here to raise questions about the co-created aspects of DST, to theorize how “voice” is produced in the digital story and as it circulates and is shared and interpreted by others (Yates 2010). A key purpose is to consider how multiple human and institutional actors negotiate and shape the story, and the extent to which narrative constraints imposed by DST problematize claims around “ordinary voices” as they are re/presented, re-contextualized, and re-mediated beyond the workshop setting (Matthews and Sunderland 2013). This is significant in thinking too about what it means to work the limits of voice in conventional, interpretive, and critical conceptions of voice in qualitative inquiry more broadly (Mazzei and Jackson 2009)

4.1 Producing “Voice”

4.1.1 Project Introduction: Bringing Voices to the Table

Participants were introduced to the project the day before the 3-day DST workshop (see Fig. 1). Members of the research team took care to introduce themselves and the research participants to one another, hoping to build familiarity and reduce any unspoken anxieties at the outset of the project. Participants were introduced to an emerging literature on children’s “lived experiences” of parental mental health problems (Gladstone et al. 2011). The group worked toward consensus around project goals, addressed outstanding questions, and identified potential barriers to participation, in order to establish a protocol for working together. Discussion revolved around the following reflexive questions:

How do my experiences shape my participation in the project? What experience have I had with (arts-based) research? What do I hope to get out of the research project? What concerns do I have or anticipate having about the challenges involved in being part of this project?

Young people wanted opportunities to educate others through participation in the project, particularly to dispel negative perceptions of mental illness. They thought adding a question about “what happens after” (living with a parent with a mental illness) was important because it addressed their own experiences more directly,

focusing on their insights and expertise about the family situation and the “intergenerational” experiences of mental health and illness. Many ideas raised in this early discussion re-emerged in the digital stories created by individual participants. At this point, the stories were being shaped in multiple ways, through the introductory discussion that included the researcher’s objectives for the project and findings from the empirical literature on families living in this context.

4.1.2 DST Workshop: Negotiating Voice

Two DST facilitators from a professional organization that offers media and digital storytelling services for community development purposes worked with the participants to design and produce digital stories during an intensive 3-day workshop (Fig. 1). The process included: script writing and voice-over recordings of first-person narratives; creating visual story content through images brought from home or photos and drawings created in situ; choosing (copyright-free) music and sound-effects to illustrate the stories; and editing visual and audio material to produce the final story using specialized software.

Participants first learned how to structure their story according to the seven story elements (Table 1), inspired by digital stories screened from previous projects. One participant, Justin, asked whether their stories had to “have a happy ending,” sensing the expectation in DST to provide closure. The facilitator pointed to one story about addiction that was not resolved because the storyteller was “still drinking and waiting for recovery.” She explained,

She [the storyteller] is still in the middle of what she is going through. You don’t have to tie everything up into a pretty bow. I won’t ask you that, but I am asking you to draw on your own strength and power, your own insight. It doesn’t have to have an ending.

Participants were also asked to consider research questions to create their stories:

What would you like others to know about your experiences coping with difficulties because your parent has a mental illness? What led to the challenges you and your family experience? What could be done to prevent these difficulties? What are your feelings about the types of help that you have received? What type of support would be most useful to you and your family?

The extent to which participants had choice in responding to the research questions was difficult to sort out and the research team and the DST facilitators from the beginning of the project openly discussed it. It remained a challenging issue that was addressed with some ambivalence by the DST facilitators, but also with flexibility and a willingness to negotiate around this on everyone’s part as in the following directive to the participants:

These are the questions that the researchers want to explore, but you don’t need to pick one and answer it. You may want to answer all of them, and it might be what happens next – some might want to be positive, others might say screw this I’m in the middle of something. The researchers want to know this, but don’t feel constricted. (Facilitator, Story Circle, Day 1)

The shaping of the story continued during the story telling circle. Participants were encouraged to tell a story and to receive feedback or questions from group members. Young people were quick to respond, finding they had many similar experiences compared to their peers, responding with understanding or giving advice about how they might think about the digital story they wanted to tell. Facilitators also played an active role in shaping participants' stories during this exercise. For example, using traffic lights as a metaphor for types of stories that could be told, participants were challenged to tell a (yellow light) story that may be difficult, but not so demanding that they would "have a nervous breakdown" (red light), or one told so often that it was too easy (green light) and lacked impact. Alex shifted her story from one she told frequently about her mother's experience of schizophrenia and how it affected the family, to a story about her own sexual abuse that she had not wanted to burden her mother with when she was not well.

The tensions that are part of negotiating "voice" were present throughout the early part of the DST process. The facilitators struggled between wanting to ensure participants had choice over the stories they would tell and giving enough direction that would result in a "good" story, which followed the structure outlined by the seven story elements for writing a DST script (see Table 1). This is illustrated in the facilitators' struggle to provide guidance around storytelling:

Process of storytelling is part of adult education process. We will give you feedback but it is a skill that needs to be learned. It can be hard. We are giving feedback out of respect because we want to help you have a story that is as good as it can be. You can take the feedback and consider it, or you can choose to not pay attention to it, because it is your story. If you feel we are pushing you, tell us to back off. I might push you hard because I think it may help your story. (Facilitator, Day 1)

The facilitators' success in meeting this challenge could be measured by the participants' adherence to the expectations of the seven story elements, evident in the brevity of the stories created (2–3 min), the use of first person narratives and a closed structure, with many story endings tending toward a more positive resolution.

Despite some of the constraints imposed on DST participants, young people seemed pleased with the stories they were able to tell. Some produced stories that were not clearly aligned with the research objectives, at least at first glance. The medium of digital storytelling seemed to enable participant "voice" because young people were able to express themselves in ways that aligned with how they wanted to be represented to others. The following examples from the analytic discussions illustrate this point, albeit slightly differently in each extract:

Yeah, I think we did choose how we wanted to represent our story. That's like the difference between telling it to a therapist or telling it in a group. Because the story has a creative component to it, so that's like how we chose to represent our story, how we chose to represent our self. . . A common thing from all of our videos is I think, a loss of choice. Like none of us really had choices about where, what happened to us, like what happened with our parents. Like we don't have a choice. And this time we actually do have a choice about what we're going to say about it. So, I think that's important. (Fia)

Being able to say exactly what you want to say and then having the images to back it up, make it go all that much deeper. I think it's a good medium to use. (Alex)

It was rather cathartic to sort of um, maybe just get things out that wouldn't otherwise have been said in normal conversation. Right? Some of the things, most of the things, a lot of the things, in the videos either deal with heavy subject matter or very personal subject matter which doesn't necessarily come out all the time within conversation, not everyone's going to understand or going to deal well with that. So I think that for at least me, you know, me personally, it was a nice little release from my otherwise normal everyday scheduled programming. (Kaye)

Art is in the eye of the beholder whereas a multi-media project, we're telling you straight up what we're saying. (William)

Overall, participants felt the digital storytelling method allowed for a deeper, more complex way of telling (and showing) a story. Fia who explained, "There is a whole world in just one story," best sums up the potential richness of the digital story. This is significant for young people who may be used to having to tell their story so often (to health and social care professionals in particular) that many routinely tell only easy, "green light" stories, even though others may become inured to hearing them. Participants saw their everyday experiences as valuable knowledge and felt a sense of mastery or agency in the choice and control they felt they had over the story they produced, if not over the events that had inspired them.

4.2 Sharing Digital Stories

4.2.1 Structured Group Analysis Discussions

From the outset of the project, beginning with recruitment, participants understood that the purpose of digital stories was to share them with others, although the extent of this sharing was to be determined later, once the stories were complete. They were eager to help other people by sharing their experiences and this contributed in large part to the reason they chose to take part in the project. Young people anticipated sharing their stories with particular audiences and some had these groups in mind when they produced the digital story. The study was designed to provide a space where participants could hold their stories at "arm's length," to analyze them individually and as a group and discuss who they wanted to share their stories with and why. Following the workshop, young people participated in four, three-hour group analysis discussions over a two-week period, in addition to a final end-of-project session, 2 months later (Fig. 1). The sessions were co-facilitated by the DST storytelling facilitators in collaboration with the researchers (BG and ES). Analytic activities involved small and whole-group exercises, including "fun" activities such as a rhythm circle and collective poem exercises that did not rely heavily on scholarly skills in order to mitigate power differentials between young people and adults and those with higher degree training during this process (Thomas and O'Kane 1998).

During a "head, heart, and feet" exercise, participants were asked to reflect on their thoughts and emotions during the DST workshop process and why their cognitive and emotional responses mattered to the stories they had created and

were now thinking about sharing with others. Other exercises were used to help them think about the risks and benefits of telling stories, the challenges and strengths of each story, how visual and audio content deepen the interpretation of the story, as scripted, and spoken, and what it was like to share their stories with each other for the first time. Participants added more information about themselves to each of their stories. They were asked to provide a story synopsis and assign key words and discussion questions for each story. The end-of-project discussion involved reviewing a preliminary analysis and interpretation of the study data, which the researchers (BG and ES) added to and brought back to the group for reflection after a two-month hiatus. The discussion included initial responses from the first viewing of their digital stories by the project advisory group in a separate meeting (clinicians, educators, a policy maker, and a young person with a parent with mental health challenges). During the final meeting with the participants, they were asked to recommend knowledge dissemination strategies for their stories and which audiences they wanted the researchers to address.

The participatory analysis added participants' voices to the project in a different way, by creating a space for critical self-reflection and collaborative sense making, and this enabled each of them to further shape how their stories might be heard. The participants' *and* the researchers' understanding of the "lived experience" of young people managing in the context of having a parent with mental health challenges was deepened through the interactive and dynamic analytic discussions (Nind 2011). As researchers who participated in and observed and documented the entire DST process, we were also aware of an analytic responsibility we had undertaken to ensure that participants' voices were reflected in the study results and dissemination and included in our scholarly (and interpretive) engagement with one another (Drew and Guillemin 2014). Joint analytic activities were meant to facilitate whole-group interaction and to enable a mutual sharing of ideas, although we recognized the impossibility of a "level" playing field with respect to power differentials between young people and adults who have multiple forms of privilege and power. And yet the participants also recognized a distinct role for us as researchers, explicitly directing us to share their stories, what to emphasize, as illustrated in the following excerpt:

Alex: Just make sure our strengths our emphasized. The fact that we do have strengths, it's not just like, you know, we're just these weak vulnerable kids who have had rough lives, like that's not all that we are at all.

Researcher: Yeah, that's not the story you want to tell.

Alex: Okay, um. . . I think with me it's more just like, that's not really what I'm trying to make them understand, why I share my story. It's not like, oh, look at how bad my life has been, feel sorry for me. That's not what I'm trying to get to. I'm trying to get to, "Yeah, this happened but I got through it and this is what I learned from it and this is the person I am because of what happened." Like it's not all bad, necessarily (End-of-Project Discussion)

It was ethically important to have a space to talk about their stories which emerged later in discussion with the participants who wanted to discuss them and debrief about the process that led to their creation.

Because after we talked about it, it kind of like. . . . cause when you made the videos you remembered everything and talking about it made you feel better. (Suzanne, End-of-Project Discussion)

Because it's kind of like opening up a wound and irritating it, like you need some closure. It kind of added meaning to this whole project. Cause, like if you had just like, wanted our stories and said "bye bye", here's your money, it would be kind of weird (Justin, End-of-Project Discussion)

Yeah, it would feel like you're bleeding was dry and then hang us up to dry. (William, End-of-Project Discussion)

Despite their willingness to disclose difficult aspects of their "lived experience(s)," young people talked about the emotional investment involved in telling stories that re-opened old wounds and memories of past events. There were tensions, between experiences of storytelling that were cathartic (e.g., Justin felt "less bitter" about his own experience after working with the DST group), but also risky due to the challenging and potentially re-traumatizing or stigmatizing narratives they produced. They acknowledged the risk as something that could undermine their intentions, and efforts to educate others and create change, or to evoke emotions that exoticize young people and their families as "other." This was significant for young people accustomed to being labeled "at risk," which as Alex said, "doesn't tell anyone anything about you." The process of examining and analyzing deeply significant and similar experiences, and learning from and observing each other's strengths, growth, and change over the course of the project, served to strengthen their connection and to mitigate some of the discomfort and worry they experienced during the DST process and now as they anticipated sharing stories.

5 Sharing the Stories: The Digital Afterlife

The "digital afterlife" refers to the expectation that digital stories are produced so that they will be shared, which raises questions about how stories are listened to and understood as they circulate beyond the workshop setting. However, the "digital afterlife" has received less attention compared to the emphasis placed on producing digital stories (Matthews and Sunderland 2013). The inclusion of analytic discussions as part of the study design opened up a space to think more concretely about the digital afterlife with participants who had clear and specific ideas about which audiences and messages they wanted to address and their desire to influence others to make change. Several entered the study with specific messages for particular audiences, which had its own shaping effect on the story that was created. For example, Jamie had strong ideas about wanting to communicate to other transgendered youth and the service providers who work with them. Kaye wanted to talk to other young people who had lost parents to suicide and to contribute to suicide prevention efforts by sharing her story about the need for mental health resources with health professionals and policy makers. Several participants, like Lee, wanted to deliver a hopeful message to young people in similar circumstances.

During the end-of-project meeting, we discussed the “digital afterlife” to think about how stories might be received outside the study group. The project’s advisory group had viewed stories during the hiatus and provided feedback that re-ignited a heated discussion about the risk of telling stories that could lead others to feel sorry for them. This led to a robust discussion over more than one session about the concept of pity and a manuscript currently underway on this topic. Digital stories may draw on dominant discourses and clichés, which do more to conceal than to confront socially structured problems and power relations (Gladstone et al. 2012). Most of the participants did not show their digital stories to anyone outside the group, describing their reluctance and ambivalence to do so (often to protect family members, including parents). Jamie was an exception because he chose to show his story to his residential care workers. He was pleased by their response and felt his story had a significant influence on their understanding of his situation, despite the number of times he had tried to tell his story previously. His digital story seemed to produce a “voice” that could be heard by others when his own seemed to fail him. Jamie hoped this would change how residential care workers would treat others “like him” in the future (identifying himself as a transgendered male who had experienced difficulties related to his own mental distress as well as that of his mother).

This is something we didn’t actually know about you. This is something that we wish we could have known to help you more.” And it’s funny that I had spent two years trying to tell people this stuff or they had been there through most of this and didn’t actually get it until they actually saw... like visuals to... like hearing it to understand the actual impact of a person’s life. I’m definitely glad I did [show the story], especially because now, this situation that I’ve moved out. About a month before I left, not even a month, like maybe three weeks... um another transman moved into the house and now that they’ve seen my story and seen the impact that coming out can have on a family and a person themselves, I feel a lot more comfortable because I’ve paved the way for fifteen months in that house for what you should do, what you shouldn’t do. And they’ve seen the actual impact on me, that I feel a lot more comfortable when it comes to him [the new resident] because he’ll be a lot more respected, treated properly and actually have access to the resources that I’ve laid out for them. (Jamie, End-of-Project Discussion)

While researchers set the objectives and methods for the study, young people had their own motives for participating that can add to our understanding of what they hoped their stories would achieve. They talked about generating relevant substantive content based on personal information and knowledge situated in their own (intergenerational) experiences of mental health and illness. They wanted to tease out complex causes for the problems they faced and felt they had much to contribute to new knowledge in the field because they have something to say that only they can say as young people. As Alex argued, “I’m still in the middle of [the story] and I have a very different experience of it [than someone who is older]”). Young people believed in the power of knowledge for change and their stories as a way to counter stigmatizing and discriminatory narratives, and as an avenue for developing a public critique of experiences that are not “just a personal story, but one that would educate, prevent others from going through the same difficulties.”

6 Conclusion and Future Directions

The case example presented in this chapter raises questions about DST in health social science research, particularly questions about how “voice” is produced by the multiple human and institutional actors that shape the story. Recall that digital stories are often positioned as highly personal, emotive, and authentic autobiographic accounts of the lives of ordinary, often marginalized individuals. In the same way that the seven story elements facilitate the production of a “good” story, this narrative structure may be formally constraining in how “experience” is or can be articulated (Worcester 2012; Alrutz 2013). From this perspective, the narrative schema may produce a predictable story because it stresses clarity, resolve, and closure, leaving less room for ambiguity and unsettled endings. This may pose challenges for participants in how they confront or redefine meaning attributed to their life experience (Poletti 2011). These are significant questions for scholars who want to take participatory research methods with young people or other “vulnerable” populations (Komulainen 2007; Nind 2011), as well as arts-based health research methods (Boydell et al. 2012), in a more critical, theoretical direction, to think about what it means to “have” or to “give” voice and to analyze and interpret visual images in addition to text-based data. Some general direction on how to think further about participatory and DST methods and the concept of “voice” is forthcoming from other scholars like Komulainen (2007, p. 22) who cautions against a “too simplistic and/or sensationalized usage of the term voice” because young peoples’ voices should be subject to a thorough-going analysis that considers human communication dynamic, context-bound, and interactive and recognizes that there are always ambiguities present in adult/child encounters.

Similarly, Mazzei (2009, p. 7) and others (see for example, Yates 2010) argue for transformative research “practices that [can] elicit and account for the shifting and uncertain voices, spoken by participants with words, with images and with silences toward more subtle, more nuanced, more startling meanings. . .[an] undisciplining of voice that does not make easy sense and that transgresses the domesticated voice that we are accustomed to hearing, knowing and naming. Such an undisciplining results in the claiming of an excessive silent voice that we cannot ‘hear’ but that speaks to us nonetheless.” As a site of cultural production rather than reproduction (Guillemin 2004), DST has much to gain and also to contribute to current scholarly debates about “voice” and other (e.g., data analysis and interpretation) methodological challenges in qualitative inquiry more broadly.

A key consideration is the extent to which DST liberates and/or constrains “voice” with respect to representation, which has been problematized more widely in critical and poststructural approaches to qualitative inquiry and “voice research” (see for example, Jackson and Mazzei 2009). Inherent to the participatory design of our study example was the shifting power dimensions among participants, researchers, and facilitators and how this influenced decisions made throughout the DST workshop and during the group analysis discussions (which moments of the larger story were selected for the digital story; how visual elements were chosen

to represent the narrative; how the story should be shared and who it should be shared with and why). Not typically reported in descriptions of DST workshops is the role that facilitators play in working with participants to shape the stories (Gubrium et al. 2013) and also researchers, who also have a vested interest in the study.

A second question concerns what happens after once the digital stories begin to circulate outside the setting in which they were produced. Our case example goes beyond the production of digital stories (and how voice is produced) to consider the “digital afterlife,” asking how singular narratives can connect the personal and the structural (or political) to effect social change (Matthews and Sunderland 2013). Despite the significance that sharing individual stories can have in local settings, as Jamie’s experience illustrated, it is important not to assume that stories shared in broader (online) contexts will find their way to appropriate audiences to instigate the type of change DST participants (and researchers) are hoping for (Matthews and Sunderland 2013).

In thinking about how stories circulate, we can question not only how “voice” is produced, but consider also the ways in which voice itself may be productive (Mazzei and Jackson 2009), influencing how others understand and create meaning out of digital stories. Matthews and Sunderland (2013) alert us to the possibility that digital stories require translation, into other forms of representation that can speak to different audiences and to audiences differently. The researcher may be charged with particular responsibility regarding the role of “translation” in DST, including expectations by storytellers like those in our study, who directed us to use their stories, but did not always want this obligation themselves. Matthews and Sunderland (2013, p. 102) describe “re-contextualization” and “remediation” as way of thinking about consciously re-shaping stories for other modes of representation. They describe the “inherently political and interpretive shifting of meanings, between genres and contexts of social activity, such as personal storytelling, research, and policy making.”

In our case, the digital stories have been re-contextualized and remediated in several ways. At the time of writing, a digital storytelling website is under construction. It is an evolving context in which stories with an online presence are remediated in a way that leads to a potential reshaping of the participant “voice” from the one produced during the interactive, face-to-face setting of the DST workshop. We have encountered challenging questions about “how much” context is required, and appropriate, for viewers who migrate to the website so that they understand how and why and in what context these digital stories were made. This is implicated also in thinking about “voice” and how others, including various (and also unseen) audiences, may have their own interpretations of the stories and what they mean (Gladstone et al. 2012). Audience “readings” will also contribute to how the young peoples’ narratives are re-shaped, as the digital stories are re/viewed and re/told in other contexts. The risk in any re-telling or remediated context is the possibility that the voice of the storyteller will be obscured, misinterpreted, compromised, or even lost altogether.

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Netnography: Researching Online Populations

75

Stephanie T. Jong

Contents

1	Introduction	1322
2	Netnography Defined	1323
3	Netnography in Health Social Science Research	1324
4	The Process of Netnography	1325
5	The Study	1325
5.1	Phases 1: Planning	1325
5.2	Phase 2: Entrée	1326
5.3	Phase 3: Data Collection	1327
5.4	Phase 4: Data Analysis	1328
5.5	Phase 5: Research Representation and Evaluation	1329
6	Conducting Ethical Netnography	1329
6.1	Online informed consent	1330
6.2	Private Versus Public Medium	1331
7	Practical Implications	1332
7.1	Lack of Face-to-Face Interaction	1332
7.2	Researcher as Participant	1333
7.3	Size of Data Set	1334
8	Conclusion and Future Directions	1334
	References	1335

Abstract

This chapter explores the transition of netnography, a consumer marketing research method, to the field of health social science research. In contemporary society, the Internet has become an essential communication and information medium. Researchers are increasingly using the Internet as a research medium for participant recruitment and data collection. Netnography, an adaptation of

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1321

ethnography, is primarily concerned with online communication as a source of data to form an understanding of a cultural phenomenon. It is through the use of this qualitative research method that holistic research about online cultures and communities can be conducted. In the provision of a common set of methodological procedures and protocols, netnography contributes to the debate of researching online populations, and innovation in appropriate settings. Using the example of a study related to fitness communities on social networking sites (SNSs), this chapter will identify key strengths, practical implications, and ethical considerations of netnography. Discussion focuses on netnography as a dynamic adaptation of a research method emerging in the field of health social sciences research.

Keywords

Netnography · Qualitative research · Innovative methods · Health research · Social networking sites · Online research

1 Introduction

The large number of active users of SNSs and the widely recognized ability of the Internet to influence society has resulted in researchers increasingly utilizing the Internet as a medium for research and the collection of data (Stewart 2005). The variety of online data sources and the emergence of online communities on SNSs has necessitated the innovative adaptation of traditional research methods, which have previously been used for studying the “real world” offline (Hine 2000). For example, traditional methods of participant and nonparticipant observation, interviewing, and survey research have been used with varying degrees of success to collect data from this “virtual reality” (Stewart 2005). The “survivability” of these methods within an online environment is dependent upon their ability to “adapt to the technology that facilitates human interaction online” (Stewart 2005, p. 395).

Researchers in marketing and consumer research have focused on the development of an innovative research method based on the ‘traditional’ research method of ethnography, ‘netnography’. Netnography captures archival and emergent social and individual online interactions. This emerging method is being used to understand the online world, interaction styles, and lived experiences of online users (Kozinets 2015). Netnography also has the potential to blend with other research methods which involve individuals posting interactions, an evolution of the practice of ethnography. Researchers note the prime advantages of netnography to include the ability to conduct ‘fieldwork’ from researcher offices (Hine 2000), the ease and low cost of data collection, the ability to connect with geographically dispersed online community groups, and the ease of collecting different types of data (Kozinets 2010). In utilizing these strengths, there has been a growing use of netnography by researchers from diverse fields (1,300 results in a systematic search of Google Scholar conducted by Bengry-Howel et al. 2011). A common set of procedures and protocols helps to aggregate common knowledge derived from netnography

(Kozinets 2015); it contributes to the debate of researching online communities and cultures, and innovation in appropriate settings.

Online research methods, such as netnography, provide novel opportunities for understanding new forms of interaction and how people create and maintain personal relationships online (Beneito-Montagut 2011) and the development of online communities and cultures. However, netnography poses several methodological challenges and a robust discussion about designing meaningful, useful and ethical online research processes is needed. This chapter will focus on: practical strengths, practical implications, and online ethical considerations of netnography, using the example of a netnographic study related to fitness communities on SNSs.

2 Netnography Defined

Robert Kozinets, the founder and leader of netnography in marketing and consumer research, presents netnography as a method which draws upon computer-mediated communications or network-based data, textual and visual, to arrive at an ethnographic understanding of an online social experience or cultural phenomenon (1997, 2002, 2010). Kozinets (2015, p. 3) describes netnography as “rooted to core ethnographic principles of participant-observation while also seeking to selectively and systematically incorporate digital approaches such as social network analysis, data science and analytics, visualization methods, social media research presence and videography.” Netnography can be explained as a means of researching online communities in the same manner that anthropologists seek to understand the cultures, norms, and practices of face-to-face communities, by observing, and/or participating in communications on publically available online forums (Nelson and Otnes 2005; Sandlin 2007). It involves ethical online conduct, online interaction, downloading, and reflection with the aim to express and help others express and share thoughts, opinions, and experiences (Kozinets 2015). This method has the potential to gather first-hand naturalistic data from computer-mediated communication.

Netnography offers researchers the opportunity to focus on new areas of social life (Nind et al. 2012). The concepts of community and culture are at the center of netnography. It is vital to understand that these concepts are unstable, transformative, and fluid “worlds of meaning” (Kozinets 2015). To explore how community and culture are adopted, these worlds of meaning, created by interacting individuals, need to be examined in order to understand their meaningfulness, and continuance. Justifiably, the emphasis of netnography is on understanding what is shared between people, the “momentary construction of common ground” (Amit and Rapport 2002, p. 11).

The data created by online communities is vast, abundant and takes many forms. Online data can be created by an individual or by a group (e.g., interactions), or even with the use of software. Digital archives are also commonly used by researchers as data. Both textual and visual data (including drawings and pictures) are common.

Sound files, audiovisual productions, and websites are also considered data and their online prevalence is rapidly increasing.

It is vital to note that netnography is not purely the downloading of data. Netnography differs from data mining or big data analysis due to the human-to-human interaction, interpretation, and integration (Kozinets 2015). Reflecting on the continuum of participation (Kozinets 2010), netnographers have the ability to negotiate their level of participation in online research. For example, netnographers have the ability to be “lurkers” within an online community without evident researcher copresence. Importantly, attention must be given to the ethnographic style of netnography. This means that the researcher should inspect, index, interpret, and expand on the data, linking to specific research positions and theoretical constructs to develop a representation of understanding (Kozinets 2015). Irrespective of how data is gathered or sourced, the netnographer’s aim is to reflectively and respectfully tell of people’s experiences, illuminated with personal stories, created artifacts and images.

3 Netnography in Health Social Science Research

Significant efforts are underway to utilize netnography in health social science research using research data from blogosphere (blogging), video casting, podcasting, forums, SNSs, and so on. Blending netnography with quantitative measures, Berger et al. (2008) explored adolescent sport participation. After using national statistics, netnography was used to identify the meaning of trends in sport participation and sport behaviors of adolescents as revealed online. In research conducted on the life experiences of infertile women going through infertility treatment and their need for social and psychological support, Isupova (2011) deemed netnography as the best method to explore online support offered to patients. Isupova found that online support had both positive and negative aspects, but the most beneficial support is that received from people who are in the same life situation. Here, netnography allowed for the investigation of physically dispersed groups who were in the same life situation. In an exploration of an online gluten-free community, Bean (2014) used a qualitative inquiry to investigate the key characteristics of this community and gain a deeper understanding of member purposes for participation. In this study, netnography offered an unobtrusive exploration of the community, yet rendered a thick description of the unique culture created online.

As the aforementioned studies demonstrate, netnography can bring many benefits to health social science research. Developing the use of netnography within these areas will allow researchers to examine human society and social relationships online, activity of communities, and the development of cultures, providing insight into people’s online behavior and an understanding of how people negotiate their Internet activity. Further strengths include the ability to investigate online communities by observing and/or participating in communications on a publically available online forum in a cost-effective manner, the ability to explore sensitive topics, and the first-hand naturalistic investigation into computer-mediated communication.

4 The Process of Netnography

In 2010, Kozinets offered a rigorous set of guidelines for the conduct of netnography, developed from six steps of ethnography. These netnographic phases include: research planning, entrée, data collection, interpretation/analysis, and research representation and evaluation. Underpinning these steps is ensuring ethical standards. These phases allow an applied and systematic approach intended to address many of the procedural, ethical, and methodological issues specific to online research. Furthermore, having guidelines allows reviewers of academic papers to have clear standards in evaluating such research (Kozinets 2015).

Adhering to the 2010 guidelines, a study about fitness on SNSs, underpinned by a social construction theoretical framework, will be used as an example (outlined below). Since completing the study, recent developments on the netnography method have been published. In 2015, Kozinets wrote on the evolution of the original phases from 5 to 12: introspection, investigation, information, interview, inspection, interaction, immersion, indexing, interpretation, iteration, instantiation, and integration. These further phases include some additions, more explicit descriptions and subdivisions of the originals, for example, greater emphasis on narrowing the community group of interest, and the use of an interactive researcher website.

5 The Study

The aim of this research was to explore the way in which online communities contribute to young women's perspectives of health and how they may be barriers or facilitators to health-oriented behaviors among this online community. Netnography was identified as the ideal approach to capture meaningful data from participants within this community. This study followed the five phases of the Netnography method. This method assisted in establishing a boundary of thinking about online fitness communities and culture, through the observation of photographs, videos, and comments posted on the SNSs, Facebook and Instagram. This study also blended netnography with individual interviews of 22 participants from the online fitness community.

5.1 Phases 1: Planning

The first step of netnography involved the selection of online fitness communities. There are various sources for exploring online communities such as bulletin boards or forums, chat-rooms, SNSs, and so on. After commencing a fundamental literature review of the research area, I became an observational participant within the online fitness community on Instagram and Facebook for 1 year, prior to data collection. This observational role allowed me to start from the outside and move on the inside to become familiar with the cultural meanings and understandings, language, interests, practices, and the rituals of being involved within the online fitness community.

Throughout this year, I was able to familiarize myself with several online fitness communities and online fitness accounts that were considered for inclusion in the study. This process ensured that the sites for netnographic fieldwork were relevant, active, substantial, heterogeneous, and data-rich. Once involved, my experiences and reflections were recorded. This is vital and will be further discussed in field noting in Phase 3.

Following the identification of the online communities, I devised appropriate research questions for inquiry. Open-ended questions were developed to allow flexibility and further discussion and inquiry. These questions provided the foundation for the research; however, they were altered over time, molded by my interaction and interpretation. An ethics application followed the decision about which online forum would be used, and the research questions for inquiry.

5.2 Phase 2: Entrée

During the observational year prior to commencing the study, I was able to firmly conceptualize how I would approach the community. As commonly used for an exploration of online culture, the researcher created an alias account, deciding on minimal one-on-one interaction with online fitness participants. It is important to consider this “spectrum of participation and observation” (Kozinets 2010, p. 75) as Kozinets stresses that the participant role provides opportunity to experience entrenched cultural understanding within the specific community of interest, an ethnographic insight. Conversely, other scholars have reasoned the value of “covert studies” of online communities (Langer and Beckman 2005; Brotsky and Giles 2007) or “observational” netnographies (Beaven and Laws 2007; Brownlie and Hewer 2007; Füller et al. 2007).

After ethical approval was granted, the Facebook and Instagram alias researcher accounts were created in order to have full access to the SNSs to conduct the netnography without the use of a personal profile, a method suited to netnography (Kozinets 2010) or online ethnographies (Grbich 2013). For this study, I followed Lamb’s (2011) recommendations from an online research project based in the United Kingdom, as well as Kozinets’ advocacy on a transparent social networking site profile. The alias researcher account provided open and truthful information about myself as a PhD student, and provided extensive information about the netnographic inquiry and university affiliation. This was also provided through comments posted to the communities on walls and pictures. Furthermore, existing academic research on fitness culture, and online health and fitness communities was offered to those interested in the account. There was no encountered resistance or negativity about the fact that I was “studying the community.” Instead, I was greeted with an interest in the research reflected by a number of online community members following my page, as well as people commenting and tagging friends.

Throughout this first phase, I found it useful to reflect on what I was studying and how I was going to study it. This also involved considering what would constitute data and how I would collect this data. It is also important at this stage to consider the

future phases of the research regarding data analysis, ethical concerns, and the overall benefits of the research (Kozinets 2015).

5.3 Phase 3: Data Collection

Kozinets (2010) describes three different types of data collection that can be involved in netnographic research: archival data, elicited data, and field note data. Archival netnographic data are saved social networking site interactions stretching back throughout time. Elicited data is new data created through researcher and participant interaction, and field note data are observations from the researcher. The online study of fitness culture included both archival data and field note data. Although data collection and data analysis are separate steps, it is important to note early that they do not occur in isolation of one another.

Once connected, I searched Facebook and Instagram for fitness accounts and pages by using a hash-tag word search. A prevalent fitness “thread” on SNSs about fitness, “#fitfam” or the “fitness family” was purposely selected for analysis due to its potentially rich field of data. Other hash-tag searches included: “#fitspo” (fitness inspiration), “#fitness”, “#girlswithmuscle”, “#inspiration”, “#femalefitness”, “#fitmotivation”, “#fitgirls”, and “#strongisthenewskinny.” These hash-tags were made popular by the posts observed in the year prior to data collection. These searches led me to a pool of pictures and comments ranging from motivational statements to pictures of “fit” bodies, revealing vast numbers of publically available posts, updating in real-time. This process linked me to fitness accounts and pages where these images and comments were abundant. Although it was not explicit what would be found by the hash-tag search, I looked for general fitness pages showing a number of female fitness photographs. Further investigation of different fitness pages on the SNSs provided me with a number of online fitness female users who were active within online communities. Although considered limited interaction, I “followed” a number of online fitness pages, involving me as a “user” in the fitness community by observing posts with other members. I followed females who used Instagram to communicate in fitness communities.

Interaction with the culture and downloading archival data occurred for four months. In line with the data “saturation” principle (Liamputtong 2013; Creswell 2014), downloading archival data continued until the investigation did not provide new insights on theoretically important topical areas or additional themes. Although recorded, the date of data collection is superfluous as the data is logged on SNSs, with photographs and comments accessible from the past as well as present.

Forum posts were separated into those that were relevant to the research questions, and those that were off topic. Textual and visual data were also captured through NVivo (a computer-assisted software analysis tool) for Facebook and Evernote (a screen capture tool) for Instagram, including field notes. All relevant data were uploaded to Microsoft Excel. The data collected included dates of observation and retrieval, comments from community members on a post, the number of likes attributed to a post, how many times the post had been shared, and how many

posts were linked to a hash-tag. This allowed the highly pertinent voices of participants to be heard, offering important perspectives to discussions of online fitness. If the post came from a specific online fitness account, their followers were documented, as well as how many people were “talking” about them at the time, which is documented on Facebook. The names of pages where I collected data were posted to my alias accounts for social networking site users to view.

As mentioned above, field notes are an important way to collect data. These field notes are introspective reflections based on my personal observations, interactions, experiences of being involved within the community, and learning about particularities of the culture (Emerson et al. 2011). I found reflective prompting questions for descriptive netnographic field noting effective. Examples include: What is new? What is meaningful? What is absent from the findings that you expected to find? What do I not understand? What is it like to connect to the community members? This process enabled me to detect what was going on, and to document the journey learning of the practices, languages, rituals, members, and so on. I found this valuable in conducting the research as once I was more involved with the community and culture, I found it difficult to decipher what was “new” in the online social experiences. Field notes were documented in Word, but any software program can be used, even notes alongside the downloaded communication.

5.4 Phase 4: Data Analysis

Archival and field notes were used to organize distinct purposes and themes that emerged from the analysis of the online community. The data were analyzed using qualitative and ethnographic thematic content analysis techniques. Qualitative content analysis extends the scope of inquiry to examine meanings, themes, and patterns that may be apparent or concealed in a text (Grbich 2013). As netnography involves an inductive approach to the analysis of qualitative data, thematic content analysis was deemed an acceptable method for a textual inquiry (Silverman 2006). Thematic content analysis is the detailed examination of coding and categorizing textual information into constituent trends of consensus (Kozinets 2010; Grbich 2013; see also ► Chap. 47, “Content Analysis: Using Critical Realism to Extend Its Utility” and ► Chap. 48, “Thematic Analysis”). This research utilised a thematic content analysis following Braun and Clarke’s (2006) six-step analysis model.

The textual content of the posts was analyzed to determine the kind of “fitness-” or “health”-related discussion that emerged from the community relevant to the theoretical framework of social constructionism. This analytical approach aimed to allow the communicative meaning latent within the Instagram and Facebook data to emerge, and to witness experiences and the formation of “fitness culture” via this media. These themes and patterns informed interview questions for the second part of the study.

In qualitative research, coding can be performed either manually or electronically using software (Liamputtong and Serry 2017; Serry and Liamputtong 2017). Numerous computer-assisted qualitative data analysis software (CAQDAS)

programs (e.g., NVivo, QualPro, NUD.IST) are available and widely used (see also ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). There is debate about the use of electronic coding/software; arguments against the use of software include distancing the researcher from the data through the use of “auto-coding” (Fossey et al. 2002), the lack of meaning making, and reflective engagement with the textual data (Kidd and Parshall 2000) and concerns about validity and reliability (Welsh 2002). However, when working with large datasets, as with a netnography, electronic coding software such as CAQDAS provides a means of analyzing a greater quantity of data (Serry and Liamputtong 2017). Other advantages of using CAQDAS are efficiency in the coding process, and the ability to efficiently manage, code, and analyze large and complex datasets (Kozinets 2010; Serry and Liamputtong 2017). Auto-coding electronic techniques were not used within the study. NVivo was used to manage and catalogue the large dataset and, for ease, in organizing the data in to codes and categories.

5.5 Phase 5: Research Representation and Evaluation

Standards of excellence need to be adhered to in order to write, present and report research findings from netnography. Previously, evaluative standards for qualitative research, and particularly those pertaining to developing online research, have been criticized for being unclear (Kozinets 2010). Kozinets (2010) builds on Denzin and Lincoln’s (2005) evaluative positions for judging qualitative research to develop a set of netnographic quality standards aimed at inspiring netnographic quality. Within the current study, the ten recommended evaluation standards were reflected upon throughout the course of the research. They are named: coherence, rigour, literacy, groundedness, innovation, resonance, verisimilitude, reflexivity, praxis and intermix (Kozinets 2010). These underpinned my actions as a netnographic researcher, prompted discussions, helped to build ideas, and acted as a toolkit to aid with evaluation prior to representing the research through writing.

6 Conducting Ethical Netnography

The Internet and SNSs are proving to be ‘ethically problematic’ fields for researchers. Although ethics and policies developed in the context of offline research apply to online investigations, questions about the need for and means of obtaining informed consent, anonymity, and the conceptualization of public versus private information pose certain problems for conducting research online. Some emerging literature is beginning to provide useful insights into social media and ethical guidelines (Fielding et al. 2008; Zimmer 2010; James and Busher 2015).

In this study, Kozinets’ (2002) four recommendations of ethical research procedures when using netnography were followed. These were: (1) The researchers should fully disclose their presence, affiliations, and intentions to online community members during any research; (2) the researchers should ensure confidentiality and

anonymity of informants; (3) the researchers should seek and incorporate feedback from members of the online community being researched; and (4) the researcher should take a cautious position on the private-versus-public medium issue. Ethical clearance for the project was gained by following the procedures outlined by the associated institution.

6.1 Online informed consent

The inability of participants to provide autonomous consent as part of online research has been widely and duly noted (Zimmer 2010; Lamb 2011). The accessibility of updated and instant data relating to every social phenomenon on the Internet creates concerns that the researchers could be tempted to use it as a “research playground” (Hine 2008, p. 316) without due regard to the respect of the people involved.

Kozinets’ (2002) four recommendations of ethical research procedures provides an understanding of how to ethically contact community members in order to obtain their permission, or informed consent, and to directly quote any specific postings in the research. Debates arise over the idea of archived messages viewed as human subjects’ social research (Kozinets 2015). Furthermore, it is not always possible to gain consent from the many users of an online community. Some may change or delete their account, or may no longer be involved with the community. Nevertheless, Bassett and O’Riordan (2002) suggest that this should not prevent the researching of this material.

Langer and Beckman (2005) justify their use of covert netnography where participants are not informed of the researchers’ presence; they argue that by revealing themselves as researchers in a study on a ‘sensitive’ research topic, the research project could be potentially threatened. Other researchers have also used a netnographic approach where participant statements have been used without a discussion on ethics (see Smith and Stewart 2012). Conversely, Kozinets (2015) views netnographers as cultural participants, interacting with the community, undertaking human subject’s research. Hine (2008) and Kozinets (2015) share similar views of online consent. They affirm that, where possible, researchers should ask for consent in order to lead to interesting insights that help interpret data.

Interestingly, Hine (2008) claims that there are circumstances where informed consent may not be appropriate. For example, where information is publically available such as a website or discussion forum, where “the topic is not intrusive or troubling” were the person to recognize themselves in the research, and where there is “no foreseeable harm” to possible participants, “then it might be justifiable to go ahead and collect data without seeking informed consent” (p. 317).

Within my study, my alias social networking accounts stated the nature and purpose of the research and type of data collection. Pages where data collection occurred were documented on my alias accounts. Posts were also made on each of the places of data collection informing people that posts were used from the thread. To respect the users and their data, discussion was read with reference to the context of the posts, in order to not misconstrue the meaning of their online discussions.

This transparency allowed people within the online fitness community to connect with me, but also provided documentation to see what sites had been visited and where data had been gathered. In line with Facebook's terms and conditions (Facebook 2014), I made it clear through a statement on my alias profiles, that I was an independent researcher, and that Facebook was not collecting the data. The information on these accounts also noted that data attained for the research would be made anonymous with pseudonyms. I made it a priority to maintain a high level of ethical sensitivity and adhered to the values and principles of ethical conduct to ensure expectations of consent and privacy caused no, or limited potentially damaging effects for participants (Flicker et al. 2004; Hine 2008). Whilst taking action to be respectful, and to consider the welfare of participants, the risks associated with the project, including the potential risk associated with consent, anonymity and private vs. public data were minimised as much as possible, and the potential benefits for participants and broader society were clarified to participants (National Health and Medical Research Council et al. 2007 updated May 2015). In developing a greater understanding of online fitness culture and the impact that SNS influence has on health perceptions and behaviours, the study has the potential to add to knowledge on the effect of online fitness culture on constructions of health and fitness, body image and ideals, and consequently, has the potential to positively impact future health promotion projects.

6.2 Private Versus Public Medium

On the Internet or SNSs, the lines between what is private and what is public are blurred, and ownership of data is contentious (Henderson et al. 2013). Some participants who use publicly available communication systems on the Internet have an expectation of privacy, which, as stated by Walther (2002, p. 207), is "extremely misplaced." In their research, Kozinets (2015) and Bassett and O'Riordan (2002) recognize the Internet as text-based and space-like medium, where participants create cultural artifacts. With this view, the Internet can thus be "perceived as a form of cultural production, in a similar framework to that of the print media, broadcast television, and radio" (Bassett and O'Riordan 2002, p. 235), a medium for publication, or a "public document" (Kozinets 2015, p. 136).

According to Rosenoer (1997, cited in Jacobsen 1999), posts to publicly accessible forums or sites are not private and are not protected by privacy laws. Although people know their postings are public in their accessibility through a simple Internet search, users may not expect researchers to be gathering their exchanges with others, nor does it automatically lead to the conclusion that users grant automatic consent to researchers using this data. However, as Paccagnella (1997, p. 83) notes, "that doesn't mean that they can be used without restrictions, but simply that it shouldn't be necessary to take any more precautions than those usually adopted in the study of everyday life."

The debate over who owns the data posted to public forums is important when referring to an online setting. If information is posted on a public forum or open

social networking account, the question of ownership is valid. The person who posted to a social networking site is not the only one to take ownership of a photograph. It must be recognized that the SNS also maintains part ownership (see Facebook 2014). This information is integral to netnographers who wish to undertake research requiring the use of photographs from SNSs. Ownership issues also vary due to Fair Use Doctrine in different locations around the world. Ethics for accessing comments on SNSs has been granted for other research on SNS data in a public space (Attard and Coulson 2012; Barnes et al. 2015).

To surmount these ethical dilemmas, researchers are advised to implement strategies aimed to decrease the accessibility of data by random searches. Posts made by participants that pertain to personal accounts, including names, pseudonyms, and faces, should be de-identified; i.e., removed or blurred. This will enhance the privacy and anonymity of the users. However, as a researcher, one must note that given the public nature of these pages in the first place, “there is no reasonable expectation of privacy in these conceptual spaces” (Jacobson 1999, p. 135), especially since posts may be located by Internet searches.

7 Practical Implications

The innovation and adaptation of method techniques for the study of online communities and cultures may also bring methodological challenges. These are often focused on the lack of nonverbal data. Throughout the netnographic research, I also found issues pertaining to my role as a researcher and as a participant in the online world, and with the potential size of the data set.

7.1 Lack of Face-to-Face Interaction

The Internet has created a vast increase in new online social spaces, “devoid of physicality” (Stewart 2005, p. 413). Lack of face-to-face interaction is a common objection to online research (Beaulieu 2004; Liamputtong 2013). Some researchers suggest that the online environment, where the data is represented as “text-only,” reduces social cues such as expression, emphasis, and movement (Mann and Stewart 2000). The limitations created by the lack of face-to-face interaction are deemed insignificant by Kozinets (2010) who argues that where the research focus and questions are specific to online content, a netnographic approach is sufficient. Furthermore, these limitations can be somewhat ameliorated by a blended netnography where the data collection methods connect online and offline research in a systematic manner (Kozinets 2002). Kozinets (2015) strongly advocates the inclusion of an interview stage within the new 12 phases of research. My study used this blended approach, including interviews with online fitness participants; I found this integration to offer a deeper understanding of the culture.

7.2 Researcher as Participant

Through the use of the Internet as a new medium for research, researchers now have instantaneous raw data on demand and the technological advancements to collect and analyze data. Given the open nature of many SNSs, online participant observation theoretically allows a covert position (Mann and Stewart 2000). A netnography provides the option of allowing the researchers to identify themselves among the online community, or remain a “lurker.” This can be considered problematic within netnography as the method has evolved from the assimilated nature of ethnography. It is up to the researcher to explore, interpret, and negotiate the meaning underpinning these various forms of “researcher as a participant” and to recognize the limitations associated with each process.

Within an online community, there are a diverse range of users who consider participation very differently. For example, there may be participants who play an active role in the community, or there may be those who play a marginal role in their online community, often labeled a “lurker.” This individual will usually follow the online interaction of the community without contributing to it. Other members may register some level of presence from the lurker (such as being on a “friend’s list” or “follower”), but at times (for example, when in a large online community), a lurker will go unnoticed and their role will purely involve reading posts. Noteworthy, many lurkers still think of themselves as community members (Nonnecke et al. 2006), despite their nonpublic presence.

Some researchers raise ethical issues when acting as lurkers within the online community. Specifically, this relates to the potentially unnoticed invasion of users’ privacy (Stewart 2005) (discussed later). Additionally, Beauleiu (2004) argues that by avoiding interaction, the researcher may miss information or interpretations, specifically relating to a nonvisible part of a phenomena (Hine 2000). Furthermore, Hine (2005) and Kozinets (2015) advocate active participation on the researcher’s behalf in order to access and understand the lived experiences of online community members. Contrastingly, other researchers argue that observations via lurking can reduce distorting naturally occurring behavior, and therefore data (Paccagnella 1997; Schaap 2002), and minimize the presence of the researcher (Paccagnella 1997; Grbich 2013). Within the current study, the profile pages on the SNSs selected for data collection have up to 1.5 million “followers” from around the world. As I “followed” a page, the likelihood of the page administrator or participants on the site seeing me was low. In other words, as there are high volumes of people within the community, my presence would likely be unknown. However, in order to be as transparent as possible, I constructed alias profile accounts documenting information about the current research. I also posted into community groups about my research.

As with ethnography, the netnographer becomes a vital part of the research. Through reflective field notes, the netnographer documents his/her experiences within the culture. The netnographer’s decisions of what/where to examine become data and should be documented. Through participation within the online community, the netnographer also becomes vital in the creation and analysis of data

(Kozinets 2015). Although some may consider this presence of the researcher in the field as “contamination” or that the researcher may involve oneself to the extent that objectivity is lost (Paccagnella 1997), Kozinets describes this researcher involvement as “the true nature of observation” (2015, p. 164). Paccagnella (1997) reinforces this view by advocating the role of the researcher in understanding the social reality behind the phenomena and by documenting real emerging experiences, stating, “...it is not safe to think of these data as some sort of objective reality frozen by the computer; Archived messages and logs are representations of the on-line phenomena as perceived by participants” (p. 87). Paccagnella further reflects, “...it is not intended for people uninvolved directly in interaction, and it loses part of its sense and meaning when re-read afterward by neutral observers” (p. 87).

7.3 Size of Data Set

In her article on the methodological issues arising from researching sensitive issues online, Paechter (2012) notes the potential size of the data set as a methodological challenge faced by researchers concerned with studies of online communities. In my research, I found that because the category selected was too broad, the potential size of data collection was difficult. Searching hash-tags and key words also proved difficult with the abundance of data available. Each page and profile that was visited would create new circles within the fitness community to look at, creating a larger data set.

To handle the sometimes overwhelming amounts of data that netnography can generate, Dholakia and Zhang (2004) suggest researchers be specific about what community will be under investigation. For future netnographic researchers, it is suggested to select one community group to engage the netnography with, and to specify the research questions. These decisions will limit the potential data set size and allow researchers to explore the community in greater detail in a designated time frame. Once the community is selected and specified, the researcher may classify messages by relevance to the topic, leading to a refocus on the research questions.

8 Conclusion and Future Directions

While imitative of traditional qualitative research, online qualitative research exhibits fundamental adaptations of aspects of traditional qualitative research. For example, watching what people do, listening to what they “say” through their typing and clicking, and collecting and interpreting this as data. Utilizing the strengths of technological developments, online research allows for connection to dispersed networks around the world, larger participant populations, asynchronous (not an immediate reply online, such as emails) or synchronous (immediate) communication, and cost-effective research. While researching online, social spaces inspires new methods and promotes innovative means of adapting traditional methods, it also poses significant challenges to researchers (Stewart 2005). Although these

aforementioned challenges are not necessarily new, the application of netnography has raised important questions about researching in the online environment.

The aim of this chapter has been to provide a brief overview of netnography, and to raise a number of practical implications and considerations for researchers to reflect on when considering the use of this method. In particular, a discussion has been raised about the implications of the steps of the research process. In following the steps of netnography in the study of online fitness communities and culture, I found that netnography guided the research successfully, providing an adaptable framework suitable for the disciplines of health social science research. Furthermore, by following the ethical netnography recommendations from Kozinets (2010), and other developing online ethics texts (see Mann and Stewart 2000; Fielding et al. 2008), this type of online research is becoming more achievable for researchers. An expansion of dialogue on the analysis and interpretation of digital data could benefit researchers using this method.

It is important to continue to invest in netnography as a research method in health social science research. Netnography holds promise in exploring the perspectives of online interaction, the participants in online community groups, the development of social norms and their circulation within online communities, and potentially, the voice of consumers of health interventions. Collectively, the application and integration of netnography will improve research on a new area of social life, but must be responsive and adaptive to be effective in a rapidly changing environment. The method itself is developing as evidenced by the changes from 5 to 12 phases, proving it to be responsive to the evolving research environment.

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Web-Based Survey Methodology

76

Kevin B. Wright

Contents

1	Introduction	1340
2	Advantages and Problems Associated with Online Survey Methods	1341
3	Critiques of Online Surveys	1342
4	Sampling, Measurement, and Enhancing Response Rates in Online Survey Research: Promises and Pitfalls	1344
4.1	Sampling Issues and Online Surveys	1344
4.2	Measurement Issues with Online Surveys	1345
4.3	Enhancing Response Rates Using Online Surveys	1346
5	Resources for Creating/Managing Online Surveys	1347
6	Overseeing Web-Based Survey Data Collection and Analysis Issues	1347
7	Pros and Cons of Various Web-Based Survey Platforms and Services	1348
8	Conclusion and Future Directions	1349
	References	1351

Abstract

This chapter examines a number of issues related to online survey research designed to access populations of various stakeholders in the health care system, including patients, caregivers, and providers. Specifically, the chapter focuses on such issues as finding an adequate sampling frame for obtaining samples of online populations, measurement issues, enhancing response rates, overseeing web-based survey data collection, and data analysis issues. Moreover, it examines issues such as measurement validity and reliability in web-based surveys as well as problems with selection biases and generalizability of study findings. Finally, the chapter assesses the pros and cons of using *SurveyMonkey* and *Qualtrics* as

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web-survey platforms/services and their utility for studying various online contexts that may be of interest to social science and health scholars.

Keywords

Online data collection · External validity · Response rates · Sampling · Survey research · Websurveys

1 Introduction

Over the past two decades, we have seen considerable growth in the area of online survey methodology, particularly in the areas of online survey development and implementation (Dillman 2000; Wright 2005; Lieberman 2008; Murray et al. 2009; Greenlaw and Brown-Welty 2009; Kramer et al. 2014). Paralleling the growth of online survey methodology, scholars have engaged in research to evaluate the relative merits and problems associated with online survey methods within a broad array of academic disciplines and areas (Wright 2005), including health social science researchers (Shaw and Gant 2002; Wright 2000, 2011; Konstan et al. 2005; Wright et al. 2010a). Recent trends suggest that web surveys will become increasingly prominent in the future and result in higher response rates as the general population becomes increasingly made up of “digital natives” (Kramer et al. 2014).

Understanding how to effectively design and implement online surveys as well as some of the many advantages and disadvantages of this research method can help health social science researchers study a variety of health contexts and issues. In short, understanding online survey methods is a helpful set of skills to add to one’s research method toolbox. Health social science researchers have used online surveys to access a number of segments of the population, including access to physicians, other health care workers, online support community participants, hospital staff members, patients, lay caregivers, and a variety of other web-accessible stakeholders in the health care system (Owen and Fang 2003; Konstan et al. 2005; Wright et al. 2010a; Siegel et al. 2011; Wright and Rains 2013).

Given the ubiquity of popular web survey platforms and services, such as *SurveyMonkey* and *Qualtrics*, it is easy to forget that online survey research is relatively young and constantly evolving. Until recent years, creating and conducting an online survey was a time-consuming task requiring familiarity with web authoring programs, HTML code, and scripting programs. Today, various survey authoring software packages and online survey services like *SurveyMonkey* have made online survey research much easier and faster. Yet many researchers who have been slow to move to online survey research from traditional paper and pencil survey research may be unaware of the advantages and disadvantages associated with online survey research. For example, previous research has identified numerous advantages to using online surveys over traditional survey methods, including access to individuals in distant locations, the ability to reach difficult to contact participants, and the convenience of automated data collection (Greenlaw and Brown-Welty 2009; Kramer et al. 2014). However, disadvantages of online survey research include

uncertainty over the validity of the data and sampling issues and concerns surrounding the design, implementation, and evaluation of an online survey (Kramer et al. 2014).

While a number of health social scientists currently use online surveys, many others may be unfamiliar with the process as well as the major promises and pitfalls of this research method. Other researchers may have been trained to use other researcher methods (e.g., experiments, content analysis, and so on), but they may be interested in expanding their research skills to include the use of online surveys. This chapter should be of interest to both types of scholars.

Toward that end, this chapter examines a number of issues related to using online surveys to access populations of various stakeholders in the health care system, including patients, caregivers, and providers. Specifically, the chapter focuses on such issues as finding an adequate sampling frame for obtaining samples of online populations, measurement issues, enhancing response rates, overseeing web-based survey data collection, and data analysis issues. Moreover, it examines issues such as measurement validity and reliability in web-based surveys as well as problems with selection biases and the generalizability of study findings. Finally, the chapter assesses the pros and cons of using web-based survey platforms and services like *SurveyMonkey* and *Qualtrics* and their utility for studying various online health-related communities and web portals.

2 Advantages and Problems Associated with Online Survey Methods

Research conducted on the Internet provides expanded opportunities for reaching populations of interest to health social scientists, including various stakeholders in the health care system (Eysenbach and Wyatt 2002; Wright 2005; Lieberman 2008). Emerging methodological research suggests that the Internet is an appropriate venue for survey data collection, including within health contexts (Riper et al. 2011; Kramer et al. 2014). Online surveys offer some key advantages over traditional surveys (see ► Chaps. 80, “Cell Phone Survey,” and ► 81, “Phone Surveys: Introductions and Response Rates”). For example, studies have found that recruitment advertisements on Facebook have been used successfully to recruit “hard-to-reach” populations, such as sexual minorities, people with rare diseases, veterans with post-traumatic stress disorder (PTSD), and a variety of other participants who may be of interest to health communication researchers that are not easily accessed through traditional recruitment strategies (Pedersen et al. 2015). In terms of longitudinal surveys, recruiting participants via social networking sites, like Facebook, may also benefit longitudinal retention in research, which is often affected by inability to locate participants who have moved or changed contact information (Pedersen et al. 2015). Another major advantage of web-based survey research is that it allows researchers to conveniently access populations in ways that bypass spatial, chronological, and material constraints (Evans and Mathur 2005). Moreover, web-servers are capable of collecting large numbers of data from participants who

are accessing the online survey at the same time (Evans and Mathur 2005). As a result, relatively large sample sizes can be attained within very short periods of time. For example, in one of my recent graduate research methods seminars, I had a group of Air Force Officers use their military social networks to obtain a sample of 870 people in less than 24 h. Social networking sites and other online platforms allow researchers to draw upon existing online social networks to reach large numbers of people quickly. Participants can respond to online surveys at a convenient time for themselves, and they may take as much time as they need to answer individual questions. Broadband access to the Internet also facilitates the transmission of multimedia content, which can enhance the sophistication of online surveys. For qualitative researchers, improved broadband access also allows for online focus groups and chat rooms where participants interact with each other and the interviewer/facilitator in a multimedia setting (Wright 2005). Multimedia capabilities also allow survey researchers to embed video or add more interactive measurement features to the survey (e.g., sliding bars and fuel gauge images to help them visualize different perceptions, etc., they are being asked about on the online survey).

Another important advantage of online surveys is lower cost to researchers and their institution (Evans and Mathur 2005). Compared to traditional survey methods, online surveys are much cheaper to construct and implement. In addition, more sophisticated experimental designs can take advantage of the online sphere in terms of randomly linking participants to different stimuli (e.g., YouTube videos with a specific persuasive appeal in a health message design experiment) and then having members of the control and treatment groups complete a postexperimental survey. Such features can reduce the need for physical laboratory space, the cost of incentives to get participants to come to the lab, and the cost of transferring responses to data analysis programs. Moreover, online surveys help reduce the environmental burden since participants do not need to travel to take a survey, and there is no need to print pencil-and-paper surveys (Wright 2005). Features such as automated data collection, skip patterns, automated reminders to participate survey instruments, and easy-to-download data files into SPSS or other statistical analysis software make online survey methods an attractive and less expensive way to engage in survey research compared to traditional survey methods (Couper 2008; Greenlaw and Brown-Welty 2009; Kramer et al. 2014).

3 Critiques of Online Surveys

Despite the many advantages of using online surveys, there have also been numerous critiques of online survey methods, including data security issues, sampling issues, and ethical concerns (Manfreda et al. 2008; Payne and Barnfather 2012; Curtis 2014). This section focuses on common concerns about using online survey research that stem from these criticisms.

During the first several years when online surveys started to become more popular (during the mid to late 1990s), many early studies that compared online

surveys to paper-and-pencil surveys were concerned with the issue of measurement equivalency. At the time, researchers worried that online surveys may invite measurement validity and reliability problems. However, a number of studies have been published in the past decade support an emerging consensus that both modes of data collection are generally comparable in terms of reliability and validity (Johnson 2005; Wright 2005; See Fan and Yan 2010).

Another major concern that has often been raised regarding online surveys is that online samples are not representative of the general population (Dillman 2000; Wright 2005). While this was certainly true in the early days of the Internet, in recent years more and more diverse groups of individuals (including populations of all types of patients, health-related support groups, health information communities, and so on) have found their way to cyberspace due to the reduction in costs of smart phones and other devices as well as the increased affordability of high-speed online Internet access. Studies have found that individuals do not seem to differ on many psychological and communication measures when comparing online surveys to traditional paper-and-pencil surveys (Bosnjak and Tuten 2001; Fan and Yan 2010). Another problem that can occur among researchers who use longitudinal online surveys (i.e., repeated measures) is participant attrition (Wright 2005; Murray et al. 2009). However, studies suggest that the attrition in online longitudinal surveys does not differ much from traditional surveys (Murray et al. 2009; Fan and Yan 2010). Moreover, automated email reminders appear to be a cheap and convenient way to reduce attrition in online surveys.

For researchers who use online surveys as a component of an online experimental design, the lack of experimental control can become a serious issue depending upon the nature of the experiment and the inability to have control over manipulating the environment beyond random assignment to different experimental conditions online (Wright 2005). Participants may need guidance in filling out the questionnaire, and there may be little or no opportunity for real time questions from participants. People who participate in online experiments or online surveys that ask sensitive questions may be hesitant to participate if they believe that a researcher will use a person's IP address or other information that could be used to identify their particular responses. A careful online informed consent form that contains reassurances about confidentiality and security can help to increase online survey response rates. However, a researcher needs to make sure that safeguards are built into surveys and the way in which they are disseminated that will help keep the identity of participants anonymous and secure (Couper 2008). Institutional Review Boards (IRB) at most major universities typically have some guidelines regarding the conduct of web-based research, particular in terms of participant confidentiality and privacy issues. However, depending upon the sophistication of the survey design, the IRB may have additional concerns or questions for a researcher to address. It is important for researchers to clarify the IRB guidelines for online survey research at their particular institution early in the conceptualization process to avoid added delays in terms of launching the survey.

4 Sampling, Measurement, and Enhancing Response Rates in Online Survey Research: Promises and Pitfalls

4.1 Sampling Issues and Online Surveys

Global Internet use increased around 400% between 2000 and 2009 and, today, it is a common reality in affluent Western societies (Kramer et al. 2014). In terms of sampling frames, the Internet provides many possibilities in terms of reaching potential international participants for an online survey. Such surveys are important to cross-cultural research in the health social sciences as well as building research teams comprised of scholars from different nationalities. Some scholars have argued that online surveys allow for more efficient implementation of psychological assessments when compared with traditional assessment procedures (Lieberman 2008; Shih and Fan 2008; Kramer et al. 2014). In some cases, participant recruitment on the Internet may be the most appropriate way to reach the target population. For example, if the long-term goal of a study is to establish effectiveness of an online health intervention in online cancer support communities, then a sample recruited directly from online communities would more accurately represent that population.

However, there are a number of researchers who have warned about threats to external validity (due to sampling problems) in online survey research, and they recommend certain practices to avoid (Murray et al. 2009). For example, researchers should avoid posting an open invitation link on a forum or sending out invitations to the entire target population (a census). Moreover, many respondents have a tough time distinguishing between a legitimate survey and a spam message (especially if a person is fearful that clicking on the link to the survey might infect their computer with a virus). In addition, some individuals are more drawn to a survey topic than others or may have more time than others in terms of being able to complete an online survey questionnaire. Such issues often lead to selection biases in the sampling process. Researchers need to consider how recruitment and enrollment on the Internet may present unique challenges to sample validity and representativeness (Shih and Fan 2008; Murray et al. 2009). Whenever feasible, online survey researchers should attempt to use available sampling frames to generate a probability sample of potential participants who will be invited to participate in the online survey.

Due to the global reach of the Internet, additional sampling frames of participants can be accessed conveniently and cheaply within relatively short periods of time if a questionnaire is translated and/or adapted for use in other cultures. For example Wright and colleagues (2015) conducted an online survey in China and Korea about media use, willingness to communicate about health, and weight-related stigma associated with US fast-food restaurant chain food consumption behaviors. Using contacts at universities in China and Korea, the research team was able to recruit a relatively large convenience sample of participants from both countries. However, it is important to rely on native speakers (who are members of the culture being investigated) in the construction of translated online surveys so that more nuanced regional differences in language and language use can be included in the survey

(Payne and Barnfather 2012). Researchers should not rely on more simplistic language translation tools that can be found online.

However, it is also important to point out that true global research is difficult to obtain since Internet access and use are not equally distributed worldwide, and a substantial digital divide exists between privileged and underprivileged socioeconomic groups and countries (Pullmann et al. 2009). In general, the countries with the greatest Internet access are typically more affluent, better educated, and have a higher gross domestic product (GDP) rate. Moreover, online platforms that exist in one country (e.g., Facebook in the USA) may not be available (for political or legal reasons) in other countries (such as China).

4.2 Measurement Issues with Online Surveys

Online surveys do not appear to compromise the psychometric properties of common quantitative measures (e.g., Likert-type scales, and so on), and studies have found that participants are typically not less representative of the general population than those of traditional studies (Denissen et al. 2010). The anonymity of the Internet-based platforms has been found to have a positive influence on communication behaviors that have important implications for the ubiquitous use of self-report questions on online surveys. Online anonymity has been linked in a variety of studies to feelings of reduced risk when communicating with others (Wright and Miller 2010a), increased self-disclosure of thoughts and feelings (Valkenburg and Peter 2009), reduced stigmatization of visible disabilities and health conditions (Simon Rosser et al. 2009; Wright and Rains 2013), and greater willingness to communicate with others (van Ingen and Wright 2016). Shy or anxious individuals are faced with fewer inhibitions to participate in online surveys compared to face-to-face surveys, and sensitive topics can be addressed confidentially. Because many health issues are highly sensitive and a number of diseases and health conditions are negatively stigmatized, online surveys can help health communication scholars gain access to individuals living with stigmatized health problems, people who have limited mobility due to their health issues, and people who are apprehensive about discussing sensitive health issues (who may be less willing to participate in traditional surveys).

However, it is important to recognize that creating an online survey questionnaire is not simply a case of reproducing an e-version of the paper-and-pencil survey. Formatting may need to be changed to simplify data entry, to clarify possible responses, or to avoid the possibility of submitting data before completing the survey. Due to the diversity of participants' access to the Internet, computer or smartphone differences, software differences, researchers need to make decisions about the complexity of visual design, the potential speed differences when downloading the survey on different devices, and the ability to view the whole questionnaire on a range of screen settings. Each of these design decisions can potentially influence the measurement reliability and validity of key variables on the online survey.

4.3 Enhancing Response Rates Using Online Surveys

Researchers have identified several factors that appear to increase response rates in online surveys, including personalized email invitations, follow-up reminders, pre-notification of the intent to survey, and simpler/shorter web questionnaire formats (Cook et al. 2000; Porter and Whitcomb 2003; Galesic and Bosnjak 2009). Other factors that increase response rates include: incentives, credible sponsorship of the survey, and multimodal approaches (Johnson 2005; Fan and Yan 2010). When online surveys initially appeared in widespread form in the 1990s, many researchers were concerned about inferior responses rates of online surveys (compared to mailed surveys). However, a number of studies have since found online surveys to be similar to traditional mailed surveys in terms of response rates (see Dillman 2000; Kaplowitz et al. 2004; Manfreda et al. 2008).

For example, Kaplowitz et al. (2004) found that a web survey application achieved a comparable response rate to a mail hard copy questionnaire when both were preceded by an advance mail notification. In addition, reminder mail notification had a positive effect on response rate for the web survey application compared to a treatment group in which respondents only received an e-mail containing a link to the Web survey. In terms of health social science research, van Ingen and Wright (2016) examined online coping and social support following a major life crisis using a large, representative web-based panel study in the Netherlands that yielded a response rate of 83% (2,544 respondents). Reminder emails and easy-to-use web questionnaire formatting were used in this survey, and the researchers were able to obtain a diverse sample of participants.

Another factor that appears to influence response rates in online survey is the convenience for participants. Participants can take an online survey in the comfort of their home environment. In addition, web survey questionnaire programs (e.g., *SurveyMonkey*) provide easy to navigate Likert-type, semantic differential, scales that allow participants to quickly click on a choice using a computer mouse (compared to a cumbersome phone survey or a lengthy paper-and-pencil survey). Such convenience features of online surveys appear to increase readiness to participate and may lower the compensation necessary to convince members of the target population to participate (Wilson et al. 2010).

Online surveys offer several other advantages in terms of the recruitment of participants. Researchers can rely on easy to create Internet advertisements and use online community and mailing lists, which are less time-consuming to produce and less costly to distribute, than posters, flyers, newspaper, TV, and radio advertisements. This can help extend the reach of an online survey. In addition, online surveys appear to be well suited in terms of their ability to attract greater diversity in sample by encouraging recipients (who share characteristics of interest to the researcher) to forward the message to potentially suited and interested participants. For example, including a request to forward a message about an online survey to other senior citizens if a research advertises the survey within an online community for older adults may lead to additional older adults becoming aware of (and potentially participating in) the survey. Other web communities can be used to access large

numbers of individuals based on sex, race, nationality, and other demographic variables of interest. Some online survey services (such as *SurveyMonkey*) will help researchers reach certain demographic groups via databases of people who have completed *SurveyMonkey* surveys in the past. Automatic emails can be sent to remind participants to participate in a cross-sectional survey or they can be set to remind participants in a longitudinal study to complete an online survey during designated time frames.

5 Resources for Creating/Managing Online Surveys

The particulars involved in designing, implementing, and managing an online survey are beyond the scope of this chapter. However, for scholars who are new to online survey methods, there are a number of web resources containing helpful information for scholars who want to conduct online studies, such as online pdf guides (Couper 2008), and the online course hosted by the University of Leicester (<http://www.geog.le.ac.uk/ORM/site/home.htm>) or the Web Survey Methodology project (<http://www.websm.org/>). In addition, popular online survey services like *SurveyMonkey* and *Qualtrics* offer online tutorials as well as customer support via email or phone. While such online survey services can make things easier for a researcher who is new to online survey research, they can come at a steep price, such as high subscription rates and “add on” fees for requesting particular features. Additional issues regarding online survey services will be discussed in more detail later in this chapter.

6 Overseeing Web-Based Survey Data Collection and Analysis Issues

Once the online survey has been launched, it is important for researchers to be diligent in terms of monitoring recruitment emails and postings to assure a sufficient number of recruitment messages have been sent/posted to the target population members. When posting recruitment advertisements to online communities, it is common community moderators to remove messages that have not been approved by the moderator or the community members. For researchers who are interested in surveying members of such groups, it is important to secure permission to post recruitment messages in advance of launching the survey. Many IRBs require evidence of permission from an online community moderator or leader in the form of an email or an attached letter to post recruitment messages for the study. In my own research (see Wright 2000, 2011; Wright et al. 2010b), I have found that providing community members with a link to a webpage that discusses the results of the survey once it is completed (in layperson’s terms) is a helpful way to gain access to online health-related communities.

Online survey research allows for communication between the research and participants via email if questions about particular items surface during the data collection phase. In addition, features such as the amount of time it takes a participant to

complete the survey and the time of day when the survey was taken are typically included when downloading survey data files from services like *SurveyMonkey* or *Qualtrics*. This can help a researcher decide whether or not to include or exclude data from a participant who took an extremely short (e.g., 30 s) or long (e.g., 3 weeks) time to complete the survey. Moreover, such services also include the IP addresses of the respondents' computers. *SurveyMonkey* and *Qualtrics* survey templates will recognize duplicate IP addresses, and it will not allow someone from the same IP address to submit more than one response to the online survey. As mentioned earlier, these services also include the ability to send automated reminder emails to potential participants, although it is important for the researcher to verify whether these emails have actually been sent (especially since systems can go offline due to unexpected power outages and maintenance issues).

Although it may take less time to reach a sufficient sample size using online surveys, it is important to realize that many responses from online participants may be left blank (unless the research requires participants to complete every question). As a result, what looks to be an initial sample of 300 people based on a *SurveyMonkey* data overview report, it is possible that there are large numbers of unusable responses from participants. I typically over-sample so that I receive 20–30% additional responses from participants over my target sample size goal. Most data from online surveys need to be cleaned, recoded, or transformed in some way. Most common statistical software programs (e.g., SPSS, SAS, and so on) make it relatively easy to perform these tasks. Data from surveys that use a large number of filter questions and that incorporate skip logic on the online survey may be more cumbersome to clean and organize once it has been collected.

7 **Pros and Cons of Various Web-Based Survey Platforms and Services**

New web-based survey platforms and services appear online each month, and so, it is difficult to provide a comprehensive list of all of the choices researchers have in terms of finding a web-based survey platform or service that will be most useful for the research projects. Certainly, *SurveyMonkey* and *Qualtrics* appear to be the two popular platforms/services for creating and distributing online surveys in the USA. However, there are many other platforms/service available online that range from relatively low cost to expensive, “full service” options (in which the company helps a researcher design the online survey, recruit participants, analyze data, and so on). In this section, I will discuss several pros and cons of various types of platforms and services in general as opposed to critiquing specific platforms/services.

Web-based survey platforms and services, such as *SurveyMonkey* and *Qualtrics*, provide an easy way for researchers to engage in online survey research. Standard subscription plans for these companies offer a variety of templates for different types of online surveys, tutorials, customer support, a wide range of online survey measures (e.g., short answer, Likert-type scales, semantic differential scales) and the ability to conveniently track and download response to a data analysis program (like SPSS or

SAS). However, the standard plans typically have a limit on the number of responses you can collect, and they do not include additional services, such as help with sampling, recruitment advertisement development, consultations, and data analysis. *SurveyMonkey* charges an extra fee (beyond the basic subscription plan) to download data from an online survey into SPSS or another data analysis program format. For additional fees, *SurveyMonkey* offers researchers access to a wide range of online populations (e.g., databases of people who are willing to complete online surveys that have been created by both companies) and help recruiting these individuals. *SurveyMonkey* offers services that will allow a researcher to narrow the range of online participants he or she would like to access for a particular online survey based on a multitude of demographic characteristics (i.e., age, sex, occupation, region of the country, and so on) and various other segmentation variables that are collected by *SurveyMonkey* for their participant databases. Of course, these types of potential participant databases suffer from problems such as selection bias and relevance issues (e.g., certain surveys may not be of concern or interest to people in the databases, but they may be willing to take the survey if they are being compensated by *SurveyMonkey*).

Individual subscriptions to *SurveyMonkey* and *Qualtrics* (as well as similar companies) can be expensive, but site licenses for universities and units within them tend to be reasonable in terms of cost. For researchers who wish to download qualitative data directly into programs like *Invivo* will not find this type of option when using *SurveyMonkey* or *Qualtrics*. However, there are ways to cut and paste qualitative data from SPSS or Excel into this type of qualitative data analysis program. Moreover, these companies continue to add new features for consumers on a regular basis, so they will likely become more flexible when it comes to the types of services and data management options that will be available in the future.

8 Conclusion and Future Directions

The purpose of this chapter was to introduce health social scientists to the pros and cons of conducting online survey research, including sampling, measurement, and response rate issues. Moreover, it briefly examined some resources for getting started with online survey research, best practices in terms of overseeing and managing online surveys, and some advantages of using *SurveyMonkey* and *Qualtrics* as web-based survey platforms/services. This section briefly discusses the implications of this research method for health social scientists.

For health social science researchers, there are clearly several benefits of conducting online surveys of various health care system stakeholders via the Internet which make it an attractive alternative to traditional survey methods. These include the relative ease of survey design and implementation (especially when using platforms/services like *SurveyMonkey* or *Qualtrics*) and the potential to conduct relatively large-scale surveys while eliminating the costs of stationery, postage, and administration. Most online survey creation tools and/or use of *SurveyMonkey* and *Qualtrics* do not require any programming skills, and the cost of sending multiple e-mail invitations and reminders is negligible. More sophisticated features of online

surveys allow validation checks as data are collected or randomization of respondents to different versions of the questionnaire (for experimental designs). However, it is important to remember that the cost of online survey design and implementation may increase as the complexity/sophistication of the online survey increases (especially when using *SurveyMonkey* or *Qualtrics*).

Researchers should always be concerned with sample representativeness and other factors that may undermine the external validity of the data obtained. As with traditional survey methods, studies that can use probability samples will have better external validity than nonprobability samples. Online health organization websites, such as hospitals and physician groups, often have detailed lists of providers, staff, and other key members of the organization that can be used as a sampling frame when conducting a probability sample. Patients are harder to reach through health care organizations due to patient privacy laws (e.g., HIPPA) and organizational practices that are designed to protect patient confidentiality. However, online support communities and health information websites (such as WebMD) are helpful portals for gaining access to people who are living with a variety of health problems.

Online surveys have also been found to have issues with selection bias and the inability to reach individuals who may not have quality Internet access (e.g., high speed Internet) or the latest technology (e.g., I-Phone, tablets, and so on). Unfortunately, this may include a lot of older adults and people who face a number of health disparities due to socio-economic factors. However, one promising trend appears to be the gradual adoption of computers and devices in economically disadvantaged regions of the world. While people lack access to the most up-to-date technology, they may be able to access online surveys with the technology they have (especially if the online survey questionnaire uses a more simplistic design). Other problems, such as low response rates, can often be remedied by sending multiple email reminders, reducing the complexity of the online survey instrument, and by finding key opinion leaders who are members of the online population (or segment) of interest who may be willing to promote the survey on behalf of the researcher. Such collaborations can enhance a researcher's credibility with a specific segment of the population and ease the burden of participant recruitment.

Despite these problems, online surveys allow social scientists to access unique populations of individuals facing health concerns (e.g., people who seek online support for a rare disease), people who may be difficult to survey in other contexts, and a variety of health care professionals (since most physicians and other providers can be reached online). Online surveys also allow social scientists to research populations at a quasi-global level (i.e., the global south tends to have lower access to the Internet than other regions of the world), and this may open the door to international research collaboration on a variety of health issues.

In short, online surveys offer many advantages many advantages to health social science researchers. However, the technical and methodological implications of using this approach should not be underestimated. Additional research is needed to be better understand the pros and cons of online surveys and to find designs/approaches that improve their external validity, including approaches that increase the representativeness of invited samples and limit response bias.

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Blogs in Social Research

77

Nicholas Hookway and Helene Snee

Contents

1	Introduction	1354
2	Blogging and the Confessional Society	1355
3	Blogs as Documents of Life: Two Research Case Studies	1356
4	Anonymity, Audiences, and Online Face-Work	1358
5	Data Collection	1360
6	Data Analysis	1361
7	Ethics	1362
8	Conclusion and Future Directions	1364
	References	1365

Abstract

Blogs are the quintessential early twenty-first century text blurring the boundary between private and public. In this chapter, we approach blogs as contemporary “documents of life” and offer our reflections on what blogs can offer social researchers based on our own research experiences. Blogs offer rich first-person textual accounts of the everyday, but there are practical, methodological, and ethical issues involved in doing blog research. These include sampling, collecting, and analyzing blog data; issues of representation; and authenticity; whether blogs should be considered private or public, and if the people who create them are subjects or authors. The chapter also critically reflects on the methodological and ethical implications of the different decisions we made in our own research projects. We conclude that embracing new confessional

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1353

technologies like blogs can provide a powerful addition to the qualitative researcher's toolkit and enable innovative research into the nature of contemporary selves, identities, and relationships.

Keywords

Blogs · Documents · Online ethics · Online methods · Qualitative research

1 Introduction

Recent decades have witnessed the emergence of the social web which enables users to produce and consume content at the same time as communicating and interacting with one another (Beer and Burrows 2007). The rise of Web 2.0 has reshaped social and cultural life but also significantly shifted the practice of doing social research (Liamputtong 2013; Fielding et al. 2016). This chapter addresses one aspect of Web 2.0 culture – the weblog or blog – and how it can be employed by social researchers as an innovative qualitative research method.

There is now over 15 years of work which considers the possibilities of online research methods; early influential texts include Jones (1999) and Mann and Stewart (2000). Internet research continues to offer an exciting frontier for innovative methods, as demonstrated by recent edited collections (Hine 2013; Fielding et al. 2016; Snee et al. 2016). This work continues to make practical, theoretical, and methodological contributions to within and beyond the field of online research: “these researchers study digital phenomena because they are social, and as such deserving of attention and significant within the overall concerns of their home disciplines” (Snee et al. 2016, p. 4; see also ► Chap. 75, “Netnography: Researching Online Populations,” ► 76, “Web-Based Survey Methodology,” ► 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool,” and ► 79, “Asynchronous Email Interviewing Method”).

Quantitative survey research was an early adopter of data-gathering via the internet, and this has now become embedded within mainstream social science (Coomber 1997; Dillman 2007; see also ► Chap. 76, “Web-Based Survey Methodology”). In addition, qualitative researchers have explored how traditional techniques can be transferred to the online context, including interviews (O'Connor and Madge 2001; James and Busher 2009; Salmons 2015), focus groups (Gaiser 2008), and ethnography (Murthy 2008; Kozinets 2009; Hine 2015; see also ► Chaps. 75, “Netnography: Researching Online Populations,” ► 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool,” and ► 79, “Asynchronous Email Interviewing Method”). Naturally occurring data – produced without the intervention of a researcher – has also been analyzed using large-scale quantitative approaches (Thelwall 2009; Bruns and Stieglitz 2012) and in-depth qualitative analysis (Herring 2004; Hookway 2008; Lomborg 2012). Some social scientists have put forward a case for “native” digital methods that repurpose already-existing methods and tools from online platforms and devices, rather than translating “offline” methods to internet spaces (Rogers 2013). However, this chapter puts

forward the case for the benefits of blog analysis as an accessible online method for social scientists who wish to explore “naturalistic” data drawing on traditional qualitative approaches such as thematic analysis. Blogs offer rich, first-person textual accounts for health and social researchers interested in everyday life.

This chapter introduces the “blogosphere” and the nature of blogs and blogging, before discussing how we might see blogs as contemporary “documents of life.” It suggests some benefits of blog analysis and draws on two case studies to reflect on why researchers might utilize blogs as data. The chapter then acknowledges some potential methodological issues associated with using blogs through a consideration of bloggers’ presentation of self and the implications for trustworthiness and authenticity. Guidance on data collection and analysis is offered, along with an outline of ethical considerations for researchers interested in blog analysis.

2 Blogging and the Confessional Society

Blogs became a key player in online culture in the late 1990s and early 2000s. The growth of blogging was linked to the rise of free and user-friendly blog creation services such as *Blogger* and its rising cultural popularity, demonstrated by the emergence of “A-list” celebrity bloggers like Salam Pax (aka the “Baghdad Blogger”) and media and gossip blog Gawker (Thompson 2006). The rise of blogging, like other Web 2.0 applications such as Facebook and Instagram, reflect a broader move to a “confessional society” where private sentiment has come to colonize the public sphere (Bauman 2007; Beer 2008). Personal blogs are the quintessential early twenty-first century new media, generating data that is simultaneously private and public.

Blogs are interactive and multimedia, converging text, image, video, GIFS, and other types of media into one space. The blogged about world can be almost anything. Blog styles differ within and between blogs, shifting from a confessional style to anguished vents, therapeutic self-writing, emotional outpourings, and advocating for social causes. There are different types of blogs, from “mommy,” diet, and fitness blogs to food, travel, corporate, and educational blogs. Blogs vary in style and degree of reflexivity. Some bloggers recount experiences with little self-reflection while others are highly self-reflective and self-analytical. Although the blogged-about-universe can be on almost anything, the majority of the more diary-style bloggers are writing about ordinary relationships – work, family, friendship, neighbors – and the emotional and moral lives, these relationships are embedded within. Rather than the fragmented and distracted “whatever being” some blog theorists have proposed (Dean 2010), bloggers appear to be deeply engaged in tracing and evaluating their worlds and the ethical entanglements and relationships in which these evaluations occur. While new social media like *Facebook* and *Twitter* are characterized by the brevity of the “status update” or “the tweet,” the blog format encourages a deeper engagement with self, personal expression, and community (Marwick 2008).

3 Blogs as Documents of Life: Two Research Case Studies

There are a number of practical benefits to conducting research using blogs. Blogs provide similar but far more extensive possibilities for social science researchers than offline diaries (see also ► Chap. 83, “Solicited Diary Methods”). They are publicly available, low cost, and allow researchers to gather substantial datasets. Blog data is available as immediate texts without the need for tape-recorders and transcription (Liamputtong 2013). As discussed in more detail below, online anonymity can mean bloggers can be less self-conscious about what they disclose, and blogs also enable access to harder-to-reach populations (Mann and Stewart 2000; Hessler et al. 2003; Liamputtong 2007, 2013). As with other online sources, blogs are a global phenomenon that can be utilized for small-scale comparative research as well as studies concerned with globalizing trends. As blogs are archived documents, they can be used to examine social processes over time. Blogs are, thus, a valid addition to the qualitative researcher’s toolkit and address issues of access, practicality, and capacity. Most importantly, however, they enable access to first person and spontaneous narratives of experience and action.

Blogs are part of the generation of vast “archives of everyday life” via social media which offer unique access into biographical experience and subjective understandings. In this way, blogs can be understood as a contemporary “document of life” (Plummer 2001). Documents of life are expressions or artifacts of personal life produced in the course of everyday life such as diaries, letters, biographies, self-observation, personal notes, photographs, and films. The benefits of documents of life for qualitative researchers is that they offer insight into how the social world is experienced and creatively expressed from the perspective of the individual.

In this context, blogs share similarities with diaries, and blog analysis is an analogous method to diary research. Like diaries, blogs are personal documents produced in real time, with no precise addressee (Arioso 2010). As such, blog researchers may take inspiration from “offline” diary research. Plummer (2001, p. 49) suggests that “diaries may be one of the better tools for getting at the day-to-day experiences of a personal life.” Through diary research, social actors can be understood as both observers and informants (Toms and Duff 2002).

There are a variety of diaries which can be used as raw material for research. They can be clustered into two main types: unsolicited “documents of life” (Allport 1943, p. xii), which are spontaneously maintained by respondents, and solicited “researcher-driven diaries” (Elliott 1997, p. 22), which are created and maintained at the request of a researcher. However, both forms of diaries present challenges (see also ► Chap. 83, “Solicited Diary Methods”).

In the case of unsolicited diaries (those spontaneously maintained without the researcher’s involvement), it can be difficult to identify suitable participants and ensure content meets the aims of the research. Solicited diaries, which are written for purposes of a research project, may overcome these issues but then pose additional problems in finding participants willing to create and maintain a diary over a period of time. Blogs offer a helpful solution. Blogs possess the spontaneity of naturally occurring diaries while being easier to find and access than unsolicited personal

documents. The narratives found in personal blogs are spontaneous in the sense that they are documents produced by people “carrying out their activities . . . without any link with research goals or aims” (Arioso, 2010, p. 25). It is these elements in particular that offered innovative ways of addressing the research concerns of the following case studies of qualitative blog analysis. For both projects, blogs promised a new type of “document of life” that enabled access to first person and spontaneous narratives of experience and action.

Box 1 Nicholas Hookway’s Study of Australian’s Expressions of Everyday Morality Using Blogs

Nicholas’s research explored everyday Australian moralities: the sources, strategies, and experiences of modern moral decision-making. The study focused on everyday moral worlds, something that is difficult to explore using traditional qualitative methods such as interviews that ask people *directly* about their moral beliefs (Phillips and Harding 1985). Nicholas felt it was hard to contextualize such a topic so that it is meaningful for the participant, and he was concerned that it could also result in people attempting to present themselves in a specific moral light, abstracted from the way that morality is grounded in their day-to-day lives. Blogs offered Nicholas an alternative way to “get at” spontaneous accounts of everyday morality. The study was based upon 44 Australian blogs sampled from the hosting website LiveJournal, along with 25 online interviews. Nicholas found that morality was depicted by the bloggers as an actively created and autonomous do-it-yourself project and suggested that self, body, emotions, and authenticity may play an important role in contemporary moralities Hookway (2017).

Box 2 Helene Snee’s Study of British Young People’s Gap-Year Experiences Using Blogs

Helene’s study into overseas “gap years” by British youth was driven by a similar concern with how experiences are understood and represented. Gap years – a period of “time out” overseas at transitional moments – are now a well-established activity, particular for young people before starting higher education. Helene’s interest was in representations of cultural difference, the drawing of distinctions of taste, and the implications for identity work for this potentially cosmopolitan activity. The study drew on the concept of “frames” (Goffman 1974) to consider how bloggers understand their gap years and make them meaningful for audiences. Blog analysis allowed Helene to consider what young people themselves considered important to share about their gap years. Thirty-nine blogs written by “gappers” to document their journeys were sampled, which were supplemented with nine interviews. Her findings

(continued)

Box 2 Helene Snee's Study of British Young People's Gap-Year Experiences Using Blogs (continued)

suggest that gap years tend to follow fairly standard "scripts" and reproduced ideas about value and worth that question the status of the gap year as a progressive, cosmopolitan enterprise Snee (2013b).

4 Anonymity, Audiences, and Online Face-Work

While blogs are naturally occurring text, they are still typically written for an implicit, if not explicit, audience (Hookway 2008). It is this presence, or at least potentiality of an audience, that renders blogs distinct from traditional forms of personal diary keeping. In this way, blogs are similar to other types of public text, shaped by imagined audiences as bloggers choose, select, and even inflate what they believe to be important to record and communicate. Moreover, if these are public blogs, they are visible to anyone with internet access and are interactive (Arioso 2010). The role of potential discursive display or performance is something that needs to be thought about if researchers are considering using blogs as a data source.

One such issue is how to recognize the public nature of self-display and expression that blogging entails. Blogging might be conceptualized as a disembodied form of "face-work" (Goffman 1972), concerned with the art of self-representation, impression management, and potentially self-promotion. Bloggers may strategically select and write into existence convincing life-episodes that frame themselves as "good," "moral," and "virtuous" subjects. Blogging in this scenario is just another "stage" for what Goffman (1959, p. 244) refers to as the "the very obligation and profitability of appearing always in a steady moral light."

Online anonymity, however, can disrupt the "blogging as face-work" model. The anonymity of many blogs, as opposed to trends in other social media where the standard practice is to use real-names, affords the opportunity for bloggers to write more honestly and candidly. The anonymity of blogs troubles Goffman's analysis of face-work which is premised on the social practices of face-to-face interactions. The anonymity of the online context means that bloggers may be relatively unselfconscious about what they write since they remain hidden from view. This was evident in Nicholas's research on blogging and morality, where participants often mentioned that they revealed "more of themselves" in their blog than what they called "normal life." Conversely, in Helene's research, some of the young people on gap years consciously did not disclose all in their blogs, as they were written for friends and family to follow their trips from home. The relationship with the blog audience and the level of anonymity adopted thus contextualizes the presentation of self in blog accounts.

There is a paradox built into blogging: bloggers are writing for an audience and are, therefore, potentially engaged in a type of "face-work" but at the same time they

can be anonymous or relatively unidentifiable. This tension between visibility and invisibility gives blogging a confessional quality, where a less polished and even uglier self can be verbalized. One can express one's faults, one's mishaps – whatever might be difficult to tell as we “enter the presence of others” (Goffman 1959, p. 1) in face-to-face relations. As one blogger wrote in Nicholas's study: “the whole point is to have some place where you can be anonymous in front of people you know. . . I don't know of any time that someone's mentioned in real life a thing that's been written on LJ (LiveJournal).”

Although the potential online anonymity of blogging may sidestep problems of “face-work,” the flipside is that it raises issues about possible identity play and deception. This is of course not specific to blogs as an online genre in the context of a moral panic regarding the predatory potential of the internet. Here, people going online, typically imagined as pedophiles or old men, can disguise their identities in order to prey on vulnerable young people. The image of the predatory “stranger” lurking in the dark alleys of the internet has arguably been fuelled by a lot of early internet research, which focused on the social implications of online anonymity, particularly in terms of “simulated” identity production (Turkle 1995; Danet 1998). In these accounts, the internet provides a space where an illusory, playful, and deceptive self can dominate – for example, men can pretend to be women and vice-versa.

How trustworthy then are the expressions of self that bloggers provide? How do you know what bloggers are telling you is true? They could be an elaborate fiction. Scott (1990) asks researchers when evaluating the authenticity of documentary sources to ask if the data is credible, i.e., that it is truthful and genuine. Both of us were routinely questioned on the truthfulness of blog data when presenting our research. The online anonymity of blogging raised issues about potential identity play and deception. How do you know the bloggers are “telling the truth,” was a typical question. These concerns are rooted in the mediated nature of online representations, where “[a]nonymity in text-based environments gives one more choice and control in the presentation of self, whether or not the presentation is perceived as intended” (Markham 2005, p. 809).

The question of the importance of “truthfulness” again depends on the aims and objectives of the research. While it seemed unlikely that our blog data was “faked,” this was not of crucial methodological concern. We approached the blog data as providing insight into the stories told about gap years or moral life rather than transparent representations of actual experience. Like other forms of qualitative research, this approach to blog analysis recognizes that there may be more than one equally credible account (Heath et al. 2009). Even if bloggers do not tell the “truth,” these “fabrications” would still tell us something about the manner in which specific social and cultural ideas about travel or morality are constructed. Consequently, qualitative blog analysis has much in common with wider quality concerns such as Lincoln and Guba's (1986) concept of “trustworthiness.” Moreover, concerns regarding the “authenticity” of blog accounts in terms of genuine authorship could be replaced with attempts to ensure that the bloggers are fairly represented by

the researcher – an alternative interpretation of authenticity suggested by Lincoln and Guba (1986).

However, the issue of truthfulness may be an important consideration for a researcher wanting to read off external “truths” from the textual data – for example, the researcher seeking trustworthy accounts of weight-loss or becoming a parent. Using the multimedia elements of blogs such as images and video, and the links a blogger may post to other online content or social media, can help to build up a “picture” of the events in question. Another strategy to alleviate concerns around the veracity of the data is to supplement blog data with interviews. As discussed, both the gap-year and everyday morality project combined blog data with blogger interviews. As the blogs were limited to whatever the author had chosen to record, interviews provided a means to seek clarification, to explore absences and implicit meanings, and to contextualize online representations in terms of articulations of offline experience. This form of triangulation can also provide a technique to reinforce the “trustworthiness” of the blog analysis (Lincoln and Guba 1986; Liamputtong 2013).

5 Data Collection

The first step is to establish where and how to locate blogs. The majority of weblogs are hosted by specific blog platforms. There is a range of blog platforms available. The blog landscape is dynamic, with new platforms and technologies constantly entering and evolving. Popular platforms are Blogger, WordPress, Tumblr, LiveJournal, Medium, and Weebly. Blogger and LiveJournal have existed since 1999 while Tumblr and Medium are examples of newer offerings. Different blog platforms are orientated toward different purposes. For example, Tumblr is geared toward short-form blogging, typically around reposting web-content, while Blogger and WordPress are orientated toward long-format blogging.

Most blog platforms include a search feature which allows readers to find bloggers according to demographic information such as age and location as well as interests and hobbies. This feature can also be appropriated by social researchers to sample participants. A social researcher may use a blog platform search engine to search for key terms that bear on a particular social process or phenomenon. For example, Helene searched for blogs that contained the phrase “gap year” across the blog platforms MySpace, LiveJournal, and Globenotes. General blog search engines can also be used to locate blogs. For example, researchers can use internet wide search engines such as BlogSearchEngine.org or Ice Rocket Blog Search. These too are subject to a high turnover. For example, two of the search engines – Google Blog Search (A work-around for using Google blog search is explained here: <http://www.netforlawyers.com/content/google-kills-blog-search-engine-109>) and Technorati – used on the Gap Year project are now defunct.

Platform search engines (e.g., *LiveJournal* search) and specific blog websites (e.g., weight-loss blog sites like “The 100 most inspirational weight-loss blogs”) are useful for projects focused on analyzing a definite type of experience or process such

as those provided in travel, weight-loss, or parenting blogs. However, blog researchers need to be cautioned that even when using search engines, a degree of blog “weeding” is needed as these searchers produce not only a range of irrelevant results but also spam blogs, fake blogs, discarded blogs, access-restricted blogs, and nontraditional blogs (e.g., blogs hosted on news websites or social networking sites) (Snee 2012).

Nicholas, in his research on everyday morality, used platform search engines. However, rather than searching using key phrases, Nicholas searched for a group of bloggers who met particular characteristics and then used developed selection criterion to identify suitable posts to include within the sample. Nicholas employed this technique in the everyday morality project to firstly search for bloggers within specific age ranges and locations, and then reading the blogs returned in the search results for posts that reflected on everyday moral decision-making. This approach proved to be relatively time-inefficient and produced limited results. Blogs offered rich insights into the nature of contemporary self-identity and experience, but it was frustrating matching relevant blogs to the research aims. Nicholas switched to soliciting bloggers through advertisements in *LiveJournal* communities. This solved the “digital needle in the haystack” issue where long periods of time were spent trawling blogs in the vain hope of finding relevant posts.

This approach involved inviting participants to identify their blog to the researcher using online advertisements (e.g., advertising on *LiveJournal* for bloggers who write on everyday moral concerns). This strategy is particularly appropriate for projects like Nicholas’s where the content is not linked to explicit blog types (e.g., weight-loss blogs or travel blogs) or easily retrieved via web-based blog search engines like the former *Google Blog Search*. This blog solicitation resulted in more relevant data being collected as those who were interested in taking part in the research could then contact Nicholas and direct him to specific posts on moral issues. This approach has the benefits of identification and relevance associated with solicited “offline” diary research but avoids many of the problems, as these blogs are not created and maintained at the request of a researcher.

6 Data Analysis

Most blogs are text based and thus suit conventional qualitative methods of text analysis. Blog data can be easily converted into text files for analysis or imported into computer assisted qualitative analysis software (CAQDAS) tools like NVivo or ATLAS.ti (Liamputtong 2013; see also ► Chap. 52, “Using Qualitative Data Analysis Software (QDAS) to Assist Data Analyses”). Nicholas considered using NVivo7 for the everyday morality study but in the end adopted a “manual” approach to analysis. Nicholas’s experience was that the fractured and unstructured nature of the blog data was unworkable with the linear and highly structured demands of the software. It seemed to do an injustice to the contextual richness of the blog narratives, “thinning” the data into fragmented codes (Liamputtong and Ezzy 2000, p. 118) and infringing the creative and playful dimensions of the research.

Helene, however, successfully used CAQDAS to analyze blog narratives. Projects dealing with more tightly defined research topics like Helene's work on gap-year travel may be more amenable to CAQDAS due to their more focused and structured nature.

Narrative analysis, discourse analysis, content analysis, and thematic analysis are all suitable for analyzing blog data (Huffaker and Calvert 2005; Tussyadiah and Fesenmaier 2008; Enoch and Grossman 2010; see also ► Chaps. 47, "Content Analysis: Using Critical Realism to Extend Its Utility," ► 48, "Thematic Analysis," and ► 50, "Critical Discourse/Discourse Analysis"). Nicholas and Helene's respective projects on gap years and everyday moralities are examples of thematic analysis. For the everyday morality study, narrative analysis was considered, but the segmented nature of the blogs did not seem to lend itself to a form of analysis premised on analyzing how the parts of a biographical past are "storied" into a meaningful and coherent whole (Chase 2003; Riessman 1993). For Nicholas, the blogs sampled exemplified narratives of self but they tended to develop as a "database narrative" (Lopez 2009, p. 738), where posted fragments of self are disconnected from each other.

Other researchers have analyzed the visual aspects of blogs. For example, Scheidt and Wright (2004) explored visual trends in blogs, and Badger (2004) investigated how images and illustration shape the construction and reception of blogs. Researchers need to consider whether nontextual elements such as image, video, and music are integral to the goals of the project and how these dimensions are to be best incorporated into the analysis.

7 Ethics

Drawing on naturally occurring, "found" online data presents a number of ethical issues. The key issue addressed in ethical guidelines rests on conceptualizations of the public/private divide in online spaces (Markham et al. 2012; BPS 2013; Liamputtong 2013; see also ► Chap. 75, "Netnography: Researching Online Populations"). This has implications for whether informed consent is required, and how the data is reported. There are three broad positions taken by researchers in response to this issue. The first suggests that, as documents such as blogs are publicly available and accessible, and consequently consent is not required from bloggers (Walther 2002; Liamputtong 2013). From this perspective, bloggers are treated as authors or producers – and should even be cited accordingly (Bassett and O'Riordan 2002). The second position argues that material posted online is written with expectations of privacy and should be treated accordingly (King 1996; Elgesem 2002). This means that just because blog data is available online, it should not be treated as "fair game." The differences between these first two stances thus engage with what Frankel and Siang (1999) note as the difference between technological and psychological privacy. Moreover, blogs can be viewed as part of a bloggers' identity, and the principles associated with human subjects research, such as informed consent and protection of identity need to be addressed (Markham et al. 2012). The two stances

also require blog researchers to decide if the personal blogs they wish to analyze are representations of human subjects or texts produced by authors (Lomborg 2013).

The third position towards the public/private divide suggests that the very nature of such online spaces mean there is no clear demarcation. Early work considering these issues suggested that the internet is both “publicly-private and privately public” (Waskul and Douglas 1996, p. 131). With the advent of Web 2.0 onwards and the growth of the “confessional society” (Bauman 2007), these blurred boundaries have become more apparent. Consequently, ethical guidelines for online research highlight the importance of adopting contextual approaches to resolving these issues, depending on, for example, the vulnerability of the blogger and the expectations of the privacy of online spaces (Markham et al. 2012). Privacy may be of more concern for researchers interested in personal health narratives, given the sensitivity of the subject matter (Grinyer 2007). Conversely, the gap year blogs in Helene’s study were often specifically written for a public audience, so the authors had fewer expectations of privacy.

Blog researchers must, therefore, grapple with some thorny issues regarding privacy and the protection of human subjects. The case studies from Nicholas and Helene provide one example of how to navigate these decisions but also offer alternative points to consider. In both studies, the blogs were technically private and in the public domain, hosted on platforms that offered privacy restrictions if required. The subjects discussed were public reflections on everyday experience with little potential for harm. Consent was, thus, not obtained in either study for the use of blog data.

Given the “traceability” of online material (Beaulieu and Estalella 2012, p. 24), quoting directly from the blogs could lead readers to the bloggers’ accounts. In both case studies, decisions were made to adopt Bruckman’s (2002) suggestion of “moderate disguise” when reporting the analysis. This meant that verbatim quotations were used but personable or identifiable details were disguised and no links to the blogs were provided. This addresses the Association of Internet Researchers’ guidance regarding whether data can be linked to individuals (Markham et al. 2012). The moderate disguise approach taken by Nicholas and Helene offered an appropriate minimization of harm given the contexts they researched but still retained the meaning of the narratives. Bruckman (2002) offers a “continuum of possibilities” to help researchers decide appropriate levels of protection. Other researchers, for example, suggest paraphrasing online content in qualitative personal research (Wilkinson and Thelwall 2011). Such ethical decision-making requires ongoing ethical reflection throughout the research project, and these case studies can be open to reexamination to reflect on best practice in future research (Snee 2013). Draft digital research guidelines produced by the British Sociological Association reaffirm that prescriptive rules are not appropriate and advocates “situational ethics that can allow or discretion, flexibility and innovation” (BSA 2016, online). Useful resources therefore include not only guidelines but also contextual case studies to provide researchers with the tools to make decisions rather than definitive answers (Markham et al. 2012; BSA 2016; Townsend and Wallace 2016).

In addition to ethical considerations regarding quoting from blog source material, blog researchers must also recognize issues of copyright. If bloggers are to be

regarded as authors, for example, then they should be appropriately cited. Indeed, bloggers have automatic rights regarding the reproduction of their work under US, Australian, and UK copyright law (US Copyright Office 2000; Australian Copyright Council 2005; UK Intellectual Property Office 2013). This could be a source of tension for those researchers who wish to offer greater protection to bloggers. There are allowances made under copyright legislation for “fair use” or “fair dealing” of material for the purposes of study or research, but researchers should take care regarding attribution from a legal as well as ethical standpoint.

8 Conclusion and Future Directions

This chapter has offered suggestions for social researchers who may be interested in expanding their methodological toolkit using qualitative blog analysis. It has advocated the benefits of blog data both in terms of practical advantages but also for the insights they provide into everyday life. Through gaining an understanding of the “blogosphere” and the sorts of narratives available in these contemporary “documents of life,” social scientists can explore a range of experiences, processes, and practices. There are a number of methodological issues that can be presented by blog research, including potential concerns surrounding impression management and overall trustworthiness, along with practical issues of data collection and analysis. Moreover, there are some complex ethical decisions to be made. Nevertheless, unique perspectives are offered by these unmediated and naturally occurring first-person accounts. By providing guidance and suggesting strategies to mitigate any problems, along with case studies to illustrate the potential of blog analysis, this chapter has made the case for blog analysis as a powerful method to engage with these narratives of everyday life.

In looking to the future, technological trends tend to move so quickly that it is difficult for researchers to keep up. Even while the case studies discussed in this chapter were being conducted, a “blogging is dead” discourse was circulating, along with evidence that the numbers of people who wrote and read blogs was in decline (Halavais 2016). Instead, “blog-like” activity of recording everyday life becomes spread across social media platforms – on Twitter, Instagram, Tumblr, Facebook, and the like (Pinjamaa and Cheshire 2016; Rettberg 2014, *forthcoming*). At the same time, blogs that retain a more “traditional” format have become increasingly commercialized. Individual bloggers’ roles shift from the personal to professional as they seek to monetize their blogs (Pinjamaa and Cheshire 2016), and companies/media organizations are increasingly producing content in a “blog” format (Rettberg 2014). There are political implications for the blogosphere; Halavias (2016) plots the decline of civic webspaces due to commercialization, centralization, and monopolization of blogging-like practices by large social media platforms. On a more personal level, blog audiences become more distrustful of popular bloggers in genres such as fashion and “mommy blogging” who make the transition to professionalization. Generating income through their blogging practices raises questions of the authenticity of the narratives presented (Hunter 2016; Williams and Hodges 2016).

Where does this leave qualitative blog research? Firstly, blog researchers need to acknowledge the potential shift from personal to professional blogging when analyzing narrative accounts. Secondly, those interested in contemporary documents of life may need to widen their perspective beyond the traditional blog format and find pragmatic new solutions to take account of various channels of expression across different formats. The human need to tell narratives endures however, as do the rich data available for researchers. As Rettberg ([forthcoming](#), p. 16) suggests: “On another level, things haven’t really changed that much. Online and offline, we record aspects of our lives.” Many of the benefits of blog research – of engaging with first-person accounts of everyday life – and many of the challenges – dealing with trustworthiness and ethical negotiations of privacy – also remain the same.

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Synchronous Text-Based Instant Messaging: Online Interviewing Tool

78

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Contents

1	Introduction	1370
2	Why This Method Was Developed	1371
2.1	The Interviewer Effect	1371
2.2	Potential Interviewees	1372
2.3	Need for Online Interview to Be Synchronous	1373
3	How Do You Use It?	1373
4	Method Preference	1375
5	Conclusion and Future Directions	1378
	References	1381

Abstract

This chapter presents an explanation of the use of a synchronous text-based online interviewing method, which is a method of interviewing participants online using an instant messaging service to type to each other at the same time in a conversational style. This method was originally designed to address the need to carry out interviews on a potentially sensitive subject while also achieving a continuity of private discussion. It is particularly useful for situations in which

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face-to-face or telephone interviews are inappropriate. Online text-based interviews can, therefore, act as a solution to a perennial concern in health-related research, and is an advance on the standard practices of open-ended questionnaires, email interviews, and online discussion boards. Synchronous text-based online interviewing can be offered as an additional choice to research participants, as well as used on its own if examining sensitive topics or if additional anonymity is suitable. The use of the method alongside its strengths and weaknesses will be outlined and discussed in this chapter.

Keywords

Online interview · Qualitative · Internet research · Innovative methods · Sensitive topic

1 Introduction

The synchronous text-based online interviewing method is a method of interviewing participants online using an instant messaging service to type to each other (text-based) at the same time in a conversational style (synchronous). Over the last decade, the use of technology as a research tool has begun to develop. There are three main methods of communication through a private instant messaging (IM) forum, such as Skype. These include microphones (aural-IM), web cameras (visual-IM), and an area on which to type on the screen in a conversational style (text-IM). Overall, IM is better suited for research when interview times can be organized in advance, as opposed to random cold calling. Aural-IM using a microphone is equivalent to an organized telephone interview (Feveile et al. 2007; Drew and Sainsbury 2010) and can be combined with visual-IM using a webcam in order to add communication through facial expression and body language (Hanna 2012). Although research has been investigating the use of text-only interviews through a range of methods, such as open-ended questionnaires, email interviews, and online discussion boards, these come with the limitation of asynchronicity (see ► Chaps. 76, “Web-Based Survey Methodology,” and ► 79, “Asynchronous Email Interviewing Method”). The unique feature of using an Instant Messaging service to carry out interviews is the ability to carry out a synchronous discussion with the participant (Brewer 2000). This chapter, therefore, focuses on the text-based element that the IM services provide (text-IM).

In this chapter, we explain the use of instant messaging services to carry out text-based online interviewing that has the synchronous factor to allow for the conversation to flow during the interview. The aim of this chapter is to provide information to the reader about why and how to use this synchronous text-based online interviewing method. A case study is provided from the original development and implementation of this synchronous text-based online interviewing method. This is a piece of qualitative research exploring women’s experiences of the menopausal transition, completed as part of Gemma Pearce’s doctoral research (see Pearce et al. 2010, 2011, 2013, 2014).

2 Why This Method Was Developed

Box 1 Case Study

Imagine this situation. . .

You want to carry out a qualitative research project with menopausal women. You are a 27-year-old female and the average age for menopause is 51. You decide not to recruit through the National Health Service (NHS) because that will mainly gather participants who have had a negative experience of the menopause and its related symptoms, and you want to talk to women who have had a range of experiences.

You try to recruit by going to places where there will be lots of women, such as female-only charity events. Your mum offers to help you recruit. By the end of the day, women have been offended by you approaching them about the project but your mum has been very successful. You realize that you need to understand more about how menopausal women view you as a 27-year-old who has not been through the menopause and how you might recruit more women.

You run a focus group with some menopausal women you have managed to find through your mum's friends. In this, they say that women might not want to open up to you because you are younger and haven't been through the experience yourself. They say that they may not want to talk to you face-to-face or on the phone about sensitive topics, like changes in sex drive, lubrication and pain during sex, embarrassing heavy menstrual bleeding, and changes to their bodies. They suggest that if you try and recruit them personally, they are less likely to say they are menopausal because of social stigma, and instead suggest recruitment posters in private spaces, like the back of toilet doors. They suggest that a form of online interview where they can feel more anonymous but still be engaged in a conversational form of dialogue would be better.

This was the situation that led to the development of this text-based online interviewing method. The need for these methods with this case study was largely inspired for the need for anonymity and sensitivity. This can be applied to other research topics; however, it is not a necessary requirement to use text-IM. This method is also useful to interview some hard-to-reach populations, to save research costs, carry out more convenient interviews, or simply provide an additional choice for researchers and participants to use alongside other interview methods.

2.1 The Interviewer Effect

It is important to consider the impact that the interviewer can have when interacting with the research participant. Researchers need to consider how participants' self-presentation concerns might impact on the findings and, therefore, possibly change

the accuracy of the results. Self-presentation is a complex topic based around how we judge ourselves and how we manage the image that we project to others emotionally, physically, financially, cognitively, and behaviorally (Leary 1996). This social desirability bias is especially relevant in qualitative studies, where the interviewer effect is more pertinent (Stacey and Vincent 2011). Participants may give answers to interviewers that make them appear like a “good” interviewee, seem an expert on the topic, or provide more socially acceptable responses (Smith 1995). Further, the researcher can be viewed as an authority figure, and the participant may wish to give a pleasing impression, or feel uncomfortable about opening up, when they perceive an unequal power relationship. Participants may be distracted by their interest in the researcher and start asking questions of them or be influenced by the researcher’s personal factors, such as gender, age, and clothing, in addition to the actual questions asked and their phrasing (Lewis 1995). The researcher, therefore, needs to disentangle how their active participation influences the results of the study (Dockrill et al. 2000). This means that it is important to reflect upon the research design used in each study and the resulting influence on the participants and researchers involved in this process.

2.2 Potential Interviewees

Importantly, the use of this tool has the potential to dehumanize the interviewer and disperse any perceived unequal power relationship between the researcher and the participant, distorting any social desirability bias and reducing inhibition of the interviewee (Stacey and Vincent 2011). This, in turn, potentially results in a richer and more honest interview. Consequently, the synchronous text-IM method should be especially beneficial, when interviewing hard-to-reach populations, children, or when the interview topic is of a personal, illegal, or sensitive nature. Due to the complementarity between the participant, researcher, and the research measure being used, this extra guard of anonymity will reduce the possible biases involved between the researcher and the participant, therefore, potentially increasing the validity of the interview. Even in cases where additional levels of anonymity are not needed, using this technique could encourage participants to feel more at ease and comfortable to discuss the topic in more depth compared with a face-to-face interview, while keeping more verbal and affective intimacy than in an email interview (Hu et al. 2004).

Additionally, the synchronous online interview method has been found to be useful in educational settings examining informal mobile learning across an international context (Lambrecht 2015), and carrying out sensitive program evaluations, such as resource allocation of individual members of staff (Gruba et al. 2016). The convenience of the method is also a key consideration, as a range of participant groups may prefer communication online, for example, generations where technology is the top communication method, and people with hearing difficulties or that may prefer nonverbal communication (Ison 2009; Benford and Standen 2011).

2.3 Need for Online Interview to Be Synchronous

Over recent years, researchers have been exploring a range of data collection methods using computer technology and the internet. This has enabled ease of access to larger populations and increased response rates for survey-based studies. As online questionnaires became more accessible and reliable, researchers explored the use of open-ended questions more frequently within these surveys (Dillman et al. 2009; Reardon and Grogan 2011), and through other internet-based means, such as email interviews (Murray and Sixsmith 2002; Murray 2005; Meho 2006; James 2007), online discussion boards (Seymour 2001; Moloney et al. 2004; Im et al. 2008), and conferencing software (O'Connor and Madge 2001). None of which were synchronous because the interviewer and the participant were not online at the same time. Although these methods eliminate the need to set up a mutually convenient interview time, they reduced the continuity of interaction with the interviewer and the immediacy with the topic. These methods lack the continuity of discussion that is achieved through face-to-face, telephone, and online visual/audio interviews (James and Busher 2006).

Compared with email interviews (see also ► Chap. 79, “Asynchronous Email Interviewing Method”), this synchronous text-IM method takes on a style closer to that of a conversation, while also allowing the participants to see and potentially reflect upon the dialogue so far via visual written “record.” Unlike using the visual/aural instant messaging during interviews, this method reduces the amount of personal contact, such as communication through body language, voice, and facial expression. Although this is possibly a disadvantage compared with a face-to-face interview, this technique might increase the validity through an increased level of anonymity between the participant and the researcher (Jowett et al. 2011), helping the participant feel more at ease, or providing a preferred method of communication that is more convenient to the participant (Pearce et al. 2014).

3 How Do You Use It?

Carrying out interviews using this synchronous text-based online interviewing method saves travel time and cost, and can also take place at the participant's convenient time and place, similar to telephone interviews (see also ► Chaps. 79, “Asynchronous Email Interviewing Method,” and ► 81, “Phone Surveys: Introductions and Response Rates”). So they could be at home in their pyjamas with a cup of tea, or during a break in their working day if they wanted. We recommend that the interviewer familiarize themselves with instant messaging services prior to conducting the interviews.

Interviews can be conducted using a private instant messaging service, such as Skype. During the development of this method, participants preferred the instant messaging tools that were available through a web link, rather than as software that they needed to be downloaded on to their computer. The software option provided more effort from the participants and often required more assistance before the interview. Instructions need to be provided on their use in case this is not a tool

the participant has used before. These instructions should also provide details on the use of emoticons (☺☺), so they can choose to use these to further express themselves during their typing.

To expand anonymity for the participant and so that interviewees do not need to use their own private instant messaging accounts, interviewers should set up an interviewee account. Interviewees can then be provided with the username and password to this independent research account. This can either be multiple accounts, one for each participant, or the same account can be used, but it is important to ensure the instant messaging service does need to keep a record of previous contact with that person; if so, this history needs to be deleted after each interview (ensuring you have saved the transcript). It is recommended that the interviewer is available online prior to the interview start time. Often, participants found this useful as they would sign in early to check that the login worked and ask any questions they had about the instant messaging service or the research.

Box 2 Example Instructions for Participants to Use Instant Messaging

Go to the website: www.skype.com

Click on the option “use skype online.”

You should now reach a sign in page. Use these login details:

Username: participant5000

Password: Password5000

Press the button to sign in and continue



Click on “get started.”

This will open your profile as the participant, and you should be able to see “Researcher” as your contact.

Note: It is recommended to provide print screen pictures so that the participant can double check if they are progressing correctly.

Participants should have been assigned an individual ID code during the consent stage, so that when they logon, the researcher can ask them to confirm this. The time the interview takes should be estimated as twice the length of a face-to-face interview. This allows for people to type their responses, not only because it takes longer to type than speak, but also because typing allows people to think more and generally tend to come up with longer answers. The data is text-based and, therefore, automatically transcribed, and can easily be copied, pasted, and saved into other electronic documents. As a result, if researchers wish to send the transcripts to participants, they can do this quickly. It is also optional following the interview if participants are given the opportunity to provide any further information they think of via email or another instant messaging conversation, which can then be added to the transcript.

Box 3 Example of the Beginning of a Synchronous Text-IM Interview*Researcher says:*

- Hello, it's Gemma Pearce, thank you for being part of this study ☺
- Before we start, please can you confirm your ID code (the one that you put on the consent form)?

Participant says:

- Hi, no worries, I am signing in from home and I have my cup of tea, so I am ready to go!
- Yeah, it is HJ011962Epsom

Researcher says:

- Perfect, thank you. Do you have any questions?

Participant says:

- No, I am happy with everything, thank you.

Researcher says:

- Great, if you need to leave the computer at any point (e.g., to pop to the loo or make yourself another cuppa), that's not a problem, just type 'brb' (stands for be right back).
- Are you ready to begin?

Participant says:

- Oh thanks, that is useful to know. . . I might have to let the dog out at some point.
- Yep, I am ready ☺

4 Method Preference

When this synchronous text-based online interviewing method was tested in the research with menopausal women, participants were asked which interviewing method they would prefer; 76% preferred the text-based instant messaging technique discussed in this book chapter, 12% would have preferred the face-to-face or webcam interview technique, and the remaining 12% had no preference and were

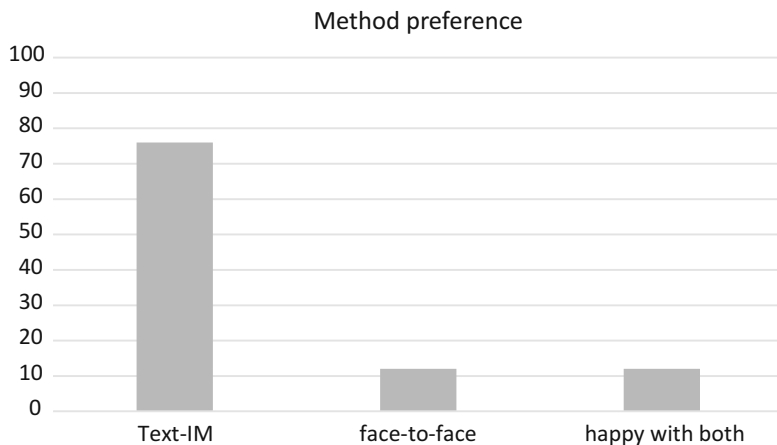


Fig. 1 Strengths and weaknesses of the method

happy using any (Fig. 1) (Pearce et al. 2014). This participant group were people who had already volunteered to participate in a synchronous online interview-based study. So, the potential for bias should be acknowledged, as those that did not want to take part were not included in the collection of this feedback. The participants put forward the suggestion that a range of methods could be offered to participants allowing them to choose their preference.

The lack of body language of voice tone meant that sentences may have been interpreted more at face value by both the interviewer and interviewee. However, as with face-to-face interviews, the interviewer could use reflexive prompts to double check they had interpreted the sentence correctly to how the interviewee intended it and encourage the interviewee to go in to more detail. Often, the participants used metaphors and similes and/or used the emoticons to help them express themselves, which often provided the researchers with rich, unique and interesting quotations about their individual experiences. Clearly, emoticons do not replace what is lost from interviews without body language, but the benefit from the additional cloak of invisibility (not seeing them or hearing their voice) provided by the tool may enable the participants to be themselves more and provide a rich interview in a different way.

During the actual process of the interview, interviewees needed more time to type their answers to the questions compared with a face-to-face interview. This allows a level of reflexivity not previously available during a synchronous interview. Participants can reflect critically on their narratives and interact in an interpretative interview developing a greater understanding of their experiences (James and Busher 2006). In addition, this enables the interviewer more time to ensure they were asking all intended questions in the interview schedule. It also allowed the researcher to double check that all relevant or unclear issues had been examined in depth. For example, sometimes an interviewee will answer a question with multiple interesting sentences, and the interviewer is spoilt for choice as to which sentence they explore first, which in turn can lead to more interesting topics. The online interview allowed the interviewer to double check that when each of

these came to a natural end that other unexplored sentences could then be examined further. This was considered an advantage from the researcher's perspective, giving the feeling that the interviews were of rich quality (Pearce et al. 2014).

A limitation we found while using online methodologies is that some participants chose not to participate in the research due to unfamiliarity with technology. However, those more familiar with communication using technological tools may prefer this form of interview. Either way, the potential for bias in interview sampling and the methods used must be considered. A potential solution may be to offer a range of interview methods to the participants, when this is appropriate to the research topic. Logistically, the text-IM interview can be carried out from any computer with the internet, allowing the interview times to be much more flexible. The interviews could be carried out by the researcher from home or work and were offered to participants at their convenience any time of the day, any day of the week. Participants were told that if they wanted to go for a toilet break or to go and get a drink during the interview then they could, they just had to say they would "be right back" or "brb" for short. Many participants said that they liked the flexibility of this. As researchers, we viewed this as an advantage of the method, as participants were able to feel more in control of the interview (Pearce et al. 2014).

The interview transcript is produced as a result of the synchronous text-IM interview, and therefore, this saves manually typing up the transcription afterwards. Although this is positive as it can save time and money, it can also be considered a disadvantage as through the process of transcription a researcher can familiarize themselves with the data during a stage of their analysis. However, as some research teams pay assistants to transcribe their interviews for them, this replaces that need. Additionally, this enabled the transcript to be sent to the participant soon after the interview, while it is still fresh in their mind, providing them with an opportunity to add anything they felt they had forgotten to say in the actual interview.

Box 4 Strengths

- Conversational form of text-based online interview (synchronous).
- Out of the participants who have used this text-IM method, the majority preferred it to face-to-face interviews.
- Provides more time for participant and researcher to reflect during the interview – potential for more in-depth interview.
- Emoticons can be used to help interviewees and interviewers express themselves. Although this does not replace personal interaction, it does provide a useful tool for online text-based communication.
- Reduces the interviewer effect on the participant.
- Allows for researcher to scroll through prose during interview, and explore any outstanding topics or clarify any areas.
- Flexibility with where and when interview can be carried out – greater convenience. More comfort for the participant can make them feel more at ease to open up to interviewer.

(continued)

Box 4 Strengths (continued)

- Interviews can be carried out internationally, conveniently, and without cost (although language barriers may need to be addressed with international studies).
- Interviewees were more in control of their interview, such as they were able to leave the computer during the interview, and choose time and place – potentially more likely to open up to interviewer.
- Interview is transcribed as a result of text-IM interviews and so this saves transcription time and cost.
- Transcripts are available straight after interview and can be sent straight to participant or reviewed by the researcher.
- Opens up research to previous participant groups that may have been hard-to-reach or communicate with, such as people with hearing difficulties.
- Participants who prefer to use technology to communicate may find this an easier form of interview.
- Can be provided on its own or offered as an option of interview methods to the participants.

Box 5 Weaknesses

- Lack of body language and tone of voice.
- Text-based interview takes longer than verbal interview.
- If researcher prefers transcription to help them absorb and reflect on data, then they are unable to do this.
- Participants who do not like technology may not participate – this may introduce a potential source of bias.
- Adds the impact of technology to the interview dynamic.
- Researchers need to familiarize themselves with instant messaging services before conducting interviews.
- An instant messaging research account should be set up for participants to use (so they do not need to use their personal accounts).
- Instructions need to be made available for participants on how to use the instant messaging service, log in, and use emoticons.

5 Conclusion and Future Directions

This chapter has aimed to present the reader with an explanation of the use of the synchronous text-based online interviewing method and provide a discussion on its strengths and weaknesses to support future researchers in deciding this methodological tool is a suitable one to use for their research.

The veil of opaqueness from not being able to see or hear each other during the synchronous text-IM interview is an aspect that is usually impossible in synchronous qualitative methods. The synchronous text-IM tool ensures a degree of confidentiality and anonymity, while still gaining depth of enquiry, where other qualitative methods potentially risk invading a participant's privacy. While body language and other nonverbal cues are useful in developing rapport with the interviewee, it may also ruin it by undermining their sense of a nonjudgmental confidante and provides the risk of the interviewee being more conservative because of their biases towards the interviewer.

This methodological tool facilitates a level of invisibility for the participant, alongside the provision of more choice and convenience in terms of location and travel (Moloney et al. 2004). The synchronous text-IM interview is a convenient, flexible, and encouraging method, allowing participants to feel comfortable and relaxed so that they could open up and discuss personal matters. Where useful and relevant, the participant cannot only be anonymous in the research report, but to the researcher as well. However, it should also be acknowledged that there is the risk of embodied dislocation if participants seize the internet-mediated interaction as an opportunity to deliberately misrepresent themselves. The veil of opaqueness the text-IM method provides can enable the participants with the freedom to manage the image (Goffman 1959; Jones 1964; Leary 1996) they project to the interviewer without the accountability of identification. This may be less likely if participants are approached as the experts of their own experience and that their real-life experiences make a valuable contribution to the research topic. Participants understanding the importance of honesty and openness about their experiences in the research helps to reduce the risk of social desirability bias and increases validity (Dickson-Swift et al. 2007).

The inability to interpret each other's body language, tone of voice, and face-to-face facial expressions with text-IM interviewing was seen as both an advantage and a disadvantage by the researchers and participants (Pearce et al. 2014). Although the text-based interview does not replace the input of body language and tone of voice in face-to-face conversation, it does provide an additional layer of invisibility that other interviews cannot provide. The text-IM method is a great improvement on open-ended questions in surveys and email interviews due to the increase in conversational fluency and the ability to express oneself. Additionally, research that has assessed emoticon use, social interaction, and online message interpretation has concluded that emoticons can reduce misinterpretation of messages by emphasizing or clarifying the implied tone in a similar manner to facial expressions in face-to-face communication (Derks et al. 2007, 2008a, 2008b, 2008c).

The question of how researchers should interpret these emoticons still remains, and this will largely depend on the epistemology of the research, for example, conversation analysis is not possible. Emoticons do not compare to the complexity of facial expression, but they do provide the researcher with further clues as to how the participant feels about the comments made, allows the researcher to adjust their reply as a result, and aid rapport building. For example, if the participant tells a joke and puts a smiley face ☺, then the researcher can smile as well helping the participant to feel more at ease. Alternatively, if the participant shows a sad face ☹, then the researcher can take more caution and react empathetically.

Instant messaging is a promising methodological tool to use in a variety of communication styles for interviews conducted globally with a variety of populations and subject matters. There is much scope for further research to examine these media and allow researchers to offer more choice and comfort to their participants regarding the interview environment and level of anonymity. There is the potential for a reduction of biases between participant and researcher on some topics, such as genital mutilation or other sensitive cultural topics. It is important for researchers to consider the potential self-presentation and impact of the research tools and group of participants being researched before designing their studies.

Box 6 Summary of the Use of Synchronous Text-Based Online Interviewing What is it?

- A method of interviewing participants online using an instant messaging service to type to each other at the same time in a conversational style.

When would you use it?

- To carry out a qualitative piece of research using interviews.
- It has also been suggested for areas of program evaluation that are sensitive, such as topics to do with resource allocation of individual members of staff (Gruba et al. 2016).

Why would you use it?

- To provide participants with an additional choice of interview method.
- To provide an additional level of invisibility (cannot see or hear each other) to help participants feel at ease and open up more, potentially increasing the validity.
- To provide a nonconfrontational interviewer–interviewee relationship and potentially encourage participants to express their thoughts more honestly.
- To provide an additional level of anonymity to participants if the research topic is sensitive, associated with embarrassment or shyness, or on legality or crime. Also if the interview may impact self-presentation or may be affected by interviewer.
- To carry out interviews further than you can travel to, while also reducing time and costs, while increasing the convenience for the participant.

With whom?

- This method could be offered to any participant groups, but may specifically be useful to offer to these specific populations.

(continued)

Box 6 Summary of the Use of Synchronous Text-Based Online Interviewing

(continued)

Participant groups:

- Who may prefer communication online
- Who are hard-to-reach
- Who may be affected by the interviewer–interviewee relationship, such as children
- With hearing difficulties or that may prefer nonverbal communication (Benford and Standen 2011; Ison 2009)

Where?

- The participant can choose a location that is convenient to them independent to the researcher's location.

How?

Some key points include (while following ethical guidelines):

- The researcher should familiarize themselves with the instant messaging service.
- Set up an instant messaging account for participants and provide them with a login and password.
- Provide instructions to participants on using an instant messaging service.
- Provide guidelines on emoticons.
- Before the interview, the researcher can log on prior to the start time to provide any support needed from the participant.
- Ensure the interview prose is saved at the end of the interview before closing the instant messaging window.
- Make sure that the instant messaging service does not store the conversation history to ensure data is only saved in a secure location.

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Asynchronous Email Interviewing Method 79

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Contents

1	Introduction	1386
2	Email as a Communication and a Research Tool	1387
3	Nine Steps to Administer Electronic Interview Via Email	1390
4	Our Experience in Using Email as an Interview Tool	1395
4.1	Delayed Responses and Absence of Punctuation	1396
4.2	Indirect Contact and Body Language	1396
4.3	Validation	1397
4.4	Informality	1397
4.5	Sampling Possibilities and Cost-Effectiveness	1398
4.6	Conclusion and Future Directions	1399
	References	1399

Abstract

This chapter explores the potential use of Internet-based communication applications (e.g., emails) as a method for gathering qualitative research data. In the era of globalized multimedia and *at-finger-tips* convenient information, electronic communication can provide answers to research inquiries in a timely manner, particularly in cases where the researcher is not required to meet face to face with the participants, or there is not need for audio-record the interview or conversation. We offer a nine-step process on how to administer an electronic interview, from selecting potential participants, interacting with them electronically, to closing the electronic encounter. We discuss the advantages and disadvantages

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of such means while drawing from a brief experience in using email to interview older adults for a research study on aging partially published elsewhere. We use the existing literature to explore the benefits and limitations of email as a research tool. We close the chapter by inviting the reader to ponder about other data collection tools in today's evolving research arena as an alternative mean to conference calls or face-to-face interviews when time and resources are restricted.

Keywords

Email · Electronic mail · Communication · Research methods · Data collection · Qualitative research

1 Introduction

It is well agreed upon that a research question should be central to, and informative of, the best fitting research methodology. Traditional ways of collecting qualitative data has been composed mainly of audio-recorded face-to-face interviews and focus group discussions with or without video recording, or written field observations or responses to predetermined questions. Although the analysis of documents, memos and records is also used, in the era of electronic communication, however, conducting an interview via Internet-based communication applications (e.g., emails) can be convenient to both the interviewer and the interviewee, while obtaining the answers in a timely manner (Ahem 2005; see also ► Chap. 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool”). In fact, electronic communication as the exchange of *meanings and information* between individuals via a common system of symbols has experienced a dramatic boom for the past two decades, not only in terms of developmental technology but also in terms of global presence (Charness et al. 2001; Adams and Neville 2012). Computer-assisted data collection as a research tool facilitated by the Internet has been used widely in product development and commercialization of goods, as well as in healthcare and sociology (de Leeuw and Nicholls 1996; Mann and Stewart 2003). Hence, the internet has experienced exponential growth as part of commerce and business (Simeon 1999; Whyte and Marlow 1999), politics (Plouffe 2009), dental and medical education (Mariño et al. 2012; Arnett et al. 2013; Cheston et al. 2013; Roy et al. 2016), and as a venue for both public and individual health promotion messages (Wong et al. 2008; Scanfield et al. 2010). In fact, more than three billion people currently use the Internet (Internet Live Statistics 2015). This boom has prompted some researchers to refer to the Internet as a cultural entity on its own, with its own environment and characteristics (Burkhalter 1999; Constantinides et al. 2010). The Internet may, for example, be used as “therapeutic” by and for older adults (Melenhorst and Bouwhuis 2004), provide support for caregivers of people with Alzheimer's disease (Alzheimer Society of Canada 2009), foster health promotion initiatives (Mariño et al. 2013), and may be a chosen environment to engage marginalized and vulnerable minority groups into research (Neville et al. 2015) (see also ► Chap. 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool”).

In turn, social media and the Internet are part of modern life where most individuals access electronic information or communicate using these means daily, almost anywhere at anytime. Although social media is most commonly used to facilitate communications, these technologies are having the same impact on research as they do in daily life with a number of existing mobile applications tailored to research (Merlien Institute 2016). A shift in the way one sees research being conducted is already occurring, which suggests that a move toward a growing number of alternative technologies to conventional pencil-and-paper or audio and video recorded qualitative data, for example. Technology will always evolve and has already changed the ways in which researchers propose and collect data where reaching participants is not bound to geographic access or temporality anymore. However, researchers need to be aware of its impact and understand the boundaries and limitations of such technologies.

Given the potential value of email as a research tool for collecting information, this chapter is organized in three parts. In the first part, we offer a more elaborated overview on the use of email as a research method for qualitative data collection with some focus on older adults. We proceed by offering a nine-step process on how to administer an electronic interview, from selecting potential participants to closing the electronic encounter. We then discuss the advantages and disadvantages of such means while drawing from a brief experience in using email to interview older adults for a research study on aging as presented in Brondani et al. 2010. We use the existing literature to explore the benefits and limitations of email as a qualitative research tool. We close the chapter by inviting the reader to ponder about other data collection tools in today's exploratory research arena as alternative means to conference calls or face-to-face interviews when time and resources are restricted.

2 Email as a Communication and a Research Tool

Associated with the Internet, the use of electronic mail (email) has increased dramatically as an effective tool of communication over the traditional *pen and paper* format (Meho 2006). Its popularity as a research tool has also increased and there is growing interest in assessing its effectiveness as such (Selwyn and Robson 1998; Benfield 2000; Cook 2012). As a research tool, email is a well-established means of distributing quantitative questionnaires (Mann and Stewart 2003; Meho 2006), interviewing people about their values and opinions (Selwyn and Robson 1998; Flowers and Moore 2003), and engaging marginalized communities (Cook 2012; Neville et al. 2015) and older adults (Brondani et al. 2010) in accessing health care and social services, for example. Nonetheless, email has been criticized as a “digital divide” by Lewis et al. (2005) since some groups may face potential barriers to internet use. It has also been thought to be abstract, impersonal, and insensitive to the nuances of nonverbal behaviors, rapport, and relationships (Melenhorst and Bouwhuis 2004); it is seen by many as a medium more appropriate to youth than to old age (McAuliffe 2003). Consequently, there are questions about the value of email as a sensitive and useful medium for interviewing people about their personal

values and opinions (Freese et al. 2006) given that studies on the topic are relatively incipient. Yet (self) stereotypes still exist for some people, including older adults not having technological competence or savvy (Harwood 2007) or Internet being something more applicable to bussines or used as leisure by the youth. Such views, however, seem to be fading away given the widespread use of the Internet (Marx et al. 2002; Hage 2008; Brondani et al. 2010; Cook 2012).

Exchange of information through email requires a certain level of computer literacy that will enable participants to use such mediums efficiently and productively (Etter and Perneger 2001; Mann and Stewart 2003; Brondani et al. 2010). The precipitous increase in the use of computers and email has done much to develop this literacy in all segments of society, and electronic jargon is used widely throughout television, radio, newspapers, and text messaging via cellular (smart) phones. Moreover, the cost of computers has steadily decreased and software programs have become more accessible for use by the general public across the world. Furthermore, the cost of accessing the Internet is not a major financial barrier to most households and free world wide web access is available in many public spaces such as coffee shops and public libraries. As a result, the profile of Internet users has changed, and continues to do so. From a predominance of users being Caucasian men between 35 and 49 years with higher than average incomes, there are now more Asian Pacific females on the same age group using the Internet (National Center for Educational Statistics 2004; Internet Live Statistics 2015). More than 10% of all Internet users are people older than 60 years of age who own personal computers in North America and are online daily more than any other age groups (National Center for Educational Statistics 2004; EMarketer 2010). In fact, approximately 83% of the population in New Zealand use the internet including those who are older, who live in rural areas and those in lower socio-economic groups (Bell et al. 2010). As revealed by the Australian Bureau of Statistics report on Household Use of Information Technology, 79% of Australian households have home Internet access, and 83% of households have access to computers (ABS 2013). Interestingly, from 1998 to 2007, household access to the Internet in Australia has almost quintupled, from 16% to 79%. Moreover, during this period, access to computers increased to more than 80%. Nevertheless, as pointed out by Lewis et al. (2005), there are socioeconomic and regional disparities in household access to computer and the Internet across Australia that contributes to the potential *digital divide* nature of the Internet: households without children under 15 years, located in exmetropolitan or remote areas, and with low-household incomes are less likely to be connected to a computer and/or the Internet (ABS 2013). This situation may be the case in many countries although half of the 40% of the world's population that have access to the Internet are located in Asia. In fact, in emerging economies such as Brazil, about 52% of its population do not have access to the Internet at home despite Brazil being one of the largest internet markets in the world (Statista 2016). On the other hand, countries with a restrictive policy on the use of the world wide web like China may have Internet availability, but have differences compared to most Western countries including Wi-Fi connections not commonly available in hotels, and access to social media networks are somewhat limited (China Highlights 2016).

Either way, when discussing the involvement of older adults in electronic communication, there is a general assumption that they are neither computer literate nor familiar with email (Whyte and Marlow 1999; Harwood 2007), and that they are disinterested in the Internet. Consequently, electronic sampling for research used to be biased toward younger and relatively affluent segments of the population (Flowers and Moore 2003). However, these assumptions have been questioned given the advance of Internet use over the past decade (Harwood 2007; Brondani et al. 2010; Cook 2012). According to an email survey (Johnson and MacFadden 1997), 70% of the seniors who use the Internet claim to have intermediate computer skills, 60% use the Internet to keep their minds active, and more than 50% send and read emails regularly. Similar positive outcomes have been found by Freese et al. (2006) and Burns et al. (2012), whereas others have pointed out that some older adults might consider email to be somewhat impersonal (Melenhorst and Bouwhuis 2004). Nonetheless, among those senior citizens who have gone online, two-thirds believed that the Internet was a reliable source of health information. It has been shown that the Internet can be used as a tool to improve older adult's (and any other age group's) knowledge and awareness of their diagnosis, treatments, and options for care, and this could eventually become a key instrument in health promotion among the aging population worldwide (Kutz et al. 2013).

In Australia, for example, almost three-quarters of those aged 55–64 years (71%) and more than one-third of those older than 65 years of age (37%) reported having surfed the Internet at any location in a month period (home, workplace, house of a neighbor or a friend or a relative, and library) (Australian Bureau of Statistics 2013). Similar findings have been reported in Canada (Statistics Canada 2010), USA (National Center for Educational Statistics 2004), and New Zealand (Bell et al. 2010) possibly because of more leisure time and discretionary income to spend on computers (Pew Internet 2010). In fact, someone who is 65 years old today has witnessed the dramatic growth of the world wide web and the introduction of electronic social networks over the past 20 years (Harwood 2007; Ramsay 2010); social media has also grown exponentially over the same period to the extent that it is now a major form of academic research (Henry and Molnar 2013; Visser 2005). Hence, many of the today's Western older adults who have approached retirement age are likely to have worked with, or been exposed to, an online environment either at the workplace, at home, or in both locations. As Harwood (2007) has discussed, these individuals may feel comfortable with email for interview purposes.

As email seems to be a leading communication tool in both personal and work contexts, it also emerges as a potential means for interview especially if there is no requirement to meet with the participant face to face, or to audio-record the conversation. Email interviews may also be used effectively if there is a need to publish the interviews on a website or other form of digital media, or if there is simply the need to get expert advice on a particular topic. Moreover, the social media has become an increasingly popular means of data collection by advertisement companies and consumer services; it is rapidly becoming an irreplaceable part of research. Its use supplements traditional research methods and can provide comparable results. As researchers already use social media to conduct the various stages of research, email for data collection will only

increase its importance while maximizing ways in which data is gathered and analyzed (see also ► Chaps. 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool,” ► 76, “Web-Based Survey Methodology,” ► 77, “Blogs in Social Research,” and ► 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool”).

Email is one of the three modes of gathering research data via the Internet. They include: (1) *online interviews*, which require real-time interaction and involve the researcher and the participant simultaneously engaging with a text-based method via “chat” or “instant messaging” software services (see ► Chap. 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool”). WhatsApp, for example, may offer a valuable tool for research activities beyond personal messaging (<https://www.whatsapp.com/>). Online interviews generate mostly qualitative data (Jowett et al. 2011); (2) *online surveys*, which pose a series of standardized questions to the participants without real-time interaction with the researcher (see ► Chap. 76, “Web-Based Survey Methodology”). Online surveys have been administered traditionally using a template format as a link distributed to participants by email (Braun and Clarke 2013). SurveyMonkey®, for example, offers an online survey development cloud-based platform that is mostly free, and invited participants complete the assigned survey and return it usually by clicking “submit.” It also allows users to design the surveys, collect responses, and conduct basic analysis on the data gathered, and (3) *email interview*, which is the focus of this chapter. As such, we will not discuss electronic surveys, texting message systems, or any other form of online and electronic data collection (see ► Chaps. 75, “Netnography: Researching Online Populations,” ► 76, “Web-Based Survey Methodology,” ► 77, “Blogs in Social Research,” and ► 78, “Synchronous Text-Based Instant Messaging: Online Interviewing Tool”). An electronic interview via email is much like a conventional interview where the researcher collects information about a participant on a given topic, usually located remotely. Below, we offer a nine-step process to administer an email interview.

3 Nine Steps to Administer Electronic Interview Via Email

In order to properly and successfully administer an email interview and get the most out of it, we suggest the steps below to give readers the tools, although some of these steps are common to conventional face-to-face interviews. Some steps are straightforward while others may need to be adapted to an electronic interview platform including obtaining ethical clearance, obtaining informed consent, and familiarizing with guidelines and legal issues around appropriate research behaviors, and participants’ confidentiality and anonymity. What follows are some steps drawn from our experience using electronic interviewing:

- **STEP 1: Prepare your interview questions**

Before starting your research study, you must develop a list of interview questions for your participant based on the area or focus of your inquiry. Area of interest aside, if

you would like to use email as an exploratory qualitative interview tool, consider having opened-ended questions (e.g., *What are your thoughts on the use of email as a means to interview participants?*) instead of close-ended inquiries (e.g., *How often to you use emails on a given day? ___less than 5 times; ___between 5 and 10 times; ___more than 10 times*).

Have your list of email interview questions ready and be also prepared to adapt or change them depending on the type of answers you are getting (see STEP 4, ahead). As a rule, each question should contain only one inquiry or concept to keep the task clear and to the point. Avoid double-barreled questions. For example, if you are interested in the issue of homelessness, first ask your participant how s/he defines somebody as homeless to then follow-up with a second question about why s/he thinks somebody gets to be homeless. Do not ask both issues (e.g., defining homeless and getting to be homeless) in one question. Do not assume that your interviewee knows the concepts or the definitions you are inquiring about. You must also consider your participants' background (including writing and language skills). There are many published manuscripts, reports, and books as well as online information on how to properly develop and frame your interview questions, so we will not discuss this topic here (see Liamputtong 2013; Serry and Laimputtong 2017, for example).

- **STEP 2: Select your participant(s)**

Based on your research area or topic, make sure your target participants can give valuable information. For example, if you would like to interview an animal activist for your class project, you would be more successful in contacting the names of individuals under animal rights or vegan food websites than names listed as reviewers of restaurants. If possible, use the internet to research your potential participant(s)' background(s) prior to contacting. This will maximize the possibility of having a better fit between your topic of inquiry and their knowledge and potential interest to be part of your study. This background exercise will also provide you with the insight you need to tailor your questions accordingly. For example, when interviewing a painter, research his/her background and accomplishments, and the types of paintings (it would help if you have seen them) to learn about their genre (modern, abstract, etc) or area (human, construction, nature, and so on), and content. Also, check on the reviews of the paintings, if available, to build your argument if that is the intention of your interview.

Also consider issues of ethics and confidentiality. Within a research environment like an academic institution or university, you must obtain ethical approval from your Research Ethics Office/Board before commencing your research. That will make sure you adhere to ethical practices and principles that are acceptable and protective of the participants.

Lastly, ponder about this question: *Is your potential participant available and willing to be interviewed via email?*

- **STEP 3: Contact your participants before administering the email interview**

It is important to contact your potential participants(s) before administering the actual email interview from the get-go. This will not only allow you to introduce

yourself and/or your organization, but also to give you the opportunity to explain the reason(s) for the interview, gauge their interest and availability, and so on.

Set the tone of the first contact to be as *inviting* as possible while being polite yet straightforward. Make sure you write a friendly invitation on your subject heading: “*Your ideas are needed,*” or “*Potential participant for an interview,*” or “*We would like to hear what you think.*” Do NOT leave it blank. Remember that in times of electronic environments and busy lives, people may delete your email without even opening it. You must get their attention and interest “right-a-way.”

Try to also do a good job in explaining how you came across their names and contact information so that your potential participants feel more at ease with you and with the request for an interview. Also, give them some ideas about you, your study/research, and the interview process itself. For example, consider something along the lines of:

‘Greetings, Mr. Mario!

I’m Augusto from the University of British Columbia in Vancouver, Canada. I came across your name and contact information from your website/company/organization. I’m currently looking for people with your expertise, and I would like to know if you would be interested in being interviewed by email. I have 5 questions on the topic of _____ that would not take more than 20 minutes of your time to respond to. You can be brief or write as much as you want to. Your answers will be confidential to me.

If you are interested, please reply to this email in the next 5 business days, so I can send you the questions and provide you with more information about the study.

Looking forward to hearing from you,

Sincerely,

Augusto, Research Assistant for Gem Laboratories

The University of British Columbia

JBM 122/2199 Wesbrook Mall

Vancouver, BC, V6T 1Z3

P: _____ / F: _____

Also, there is a possibility that your email will end up in your interviewee’s junk mail folder. Allow a week (5 business days) to send another first-contact email in case you do not hear back. There is also the possibility that the recipient of your email is not at all interested in your request.

Lastly, make sure you close the email with your contact information (and credentials) or have an email signature automatically attached to it with that information. Avoid ending the email just with your full name or worse, just with your nick name!

- **STEP 4: Pilot the interview questions**

It is always a good idea to pilot your interview questions before you send them to your interviewee to check for clarity, comprehensiveness, and readability. You can approach a couple of coworkers or friends for their help and email them the interview guide. Ask them to not only answer the questions, but also to give their written feedback on the questions themselves in terms of wording, syntax, and meaning. If feasible, you can have a face-to-face chat with them to discuss the questions and take their feedback.

This will save you time and hassle substantially since you do not want to start collecting your data realizing that your participants did not understand what you were actually asking about. Even worse is to realize this after all the textual data has been collected.

- **STEP 5: Interview your participant**

Once you received the “green” light from your interviewee to go ahead (and you have proper ethical approval where needed), start your interview email by giving information regarding the nature of the interview and the study behind it. Here, you have the opportunity to offer further yet brief insights as to what and why you are conducting such interviews. Think about “*why would the topic of the interview be relevant to your participant?*” You may describe the benefits of exploring such a topic, for example, or the need to know more about it.

Consider using the body of the email to pose your interview questions rather than as an attachment. People may not receive the attachment (in any format), may have trouble opening it, or may not want to open it.

Although the number of questions may vary, avoid more than 10 open-ended questions per communication (think about 5 questions perhaps) and provide your participants with information about the length of the email interview. Start by writing 1 or 2 general questions to begin the interview, then continue into more specific questions or topics as the interview flows. For example, begin by asking a chocolatier why they chose that as a career, then ask them additional questions specifically about their line of chocolates, the process of making it, types of cocoa used, and the locations such chocolates are being sold.

Send your interview questions all at once to avoid multiple emails (and annoying your interviewee). You can always ask for clarification on a follow-up email (see ahead). Ask your participants to take the time to answer your interview questions, but give them a timeline to send their answers back. Usually, a week or 5 business days will suffice, although you may consider an extension if they want to collaborate but need more time, or if the nature of the subject you are inquiring about requires further thinking and consideration. In all, as mentioned in STEP # 3 always provide your participant with a deadline; otherwise, you may be receiving the answers long after the research is done. Besides, a deadline often ensures that the participant completes the email interview on time, especially if there is strict deadline. Also advise your participant that if you do not hear back in the next 5 days (roughly 1 week), you will send a reminder. Ideally, you should aim to receive the answers prior to the deadline you gave them, but there is always the need to give your participants more time if that will allow them to give you more meaningful answers.

Lastly, let your participants know that, if necessary, you might send a couple of additional or clarification questions in order to fully explore the topic. This request should not come as a surprise to your participant: make sure you have this written when contacting them as per STEP # 3. We would caution you on an interview process that extends for more than two emails (the interview itself, and the follow-up clarification if needed) as people are busy and you do not want to annoy, or burn them out.

- **STEP 6: Be thankful to your participant**

After the email interview has been completed, make sure you thank them for their time and effort. Your *thank you* can be in the form of an email or telephone call, and should convey a message along the lines of:

Subject heading: *Thank you, or Gratitude, or We appreciate your help*

Dear Mr. Mario,

We would like to express our sincere gratitude and to thank you for your participation in your interview process. It was very helpful to get your insights on the questions we posed.

Have a great day,

Cheers,

Augusto, Research Assistant for Frontier Laboratories

The University of British Columbia

JBM 4561/2199 Westbrook Mall

Vancouver, BC, V6T 1Z3

P: _____ / F: _____

Depending on the budget of your study, it is not uncommon to acknowledge participation by offering a token. Such acknowledgment can take many forms and be either a gift card, money order, a discount at a particular store, or a change to enter a draw for a given product. In fact, it is not uncommon to mention or advertise this token when you first approach your potential participants, usually within the head of your email. Using the heading examples from STEP # 3, you could reword them as: “*Your ideas are needed: enter to win a _____,*” or “*Make \$_____ while being part of an email interview,*” and so on.

- **STEP 7: Save your interview material on a folder outside your mail box**

As you receive your emails, do not leave them in your mail box. Electronic files are notoriously insecure, which poses a challenge to the confidentiality of your research responses, especially when computers are connected to a shared local network. To overcome this problem, you may consider using a password-protected file in your computer desktop to store communication from our

participants. This would store your data within your computer hard drive rather than on the Internet server itself. Alternatively, you may also save your email correspondences on a password-protected folder within your hard drive or external device. Either way, it is also wise to have backed up data in case your main computer crashes.

- **Step 8: Editing and analysis**

Edit the email interview answers if needed. In most cases, especially if you are submitting the interview questions and answers to your boss or publishing the content to a website, you may need to make certain grammar and punctuation edits. Sometimes, you may need to reword the answers given in a manner that matches the style of your readership or publication, but without changing their content and meaning. Other times, you may leave “as is” if punctuation, unusual grammar and syntax, and colloquial expressions used are relevant to, or the focus of, your study. It also gives a more accurate idea of how the responses to your questions were written and interpreted.

It is not unusual to review any major editing changes with your participant(s) prior to publishing the interview. For example, if you feel the need to edit a specific quote provided to you by the participant(s), contact the subject(s) before publication to clarify that you have their permission to edit their quote. That would avoid the “*he said, she said*” scenario and worse, any litigation about what was said that way it was said. But more often than not, participants’ names are seldom used unless you got their approval to do so.

- **Step 9: Make yourself available**

Provide your participants with information about yourself and your study. Also give them the time to research your background, if necessary. Some interviewees may want to verify your identity and credibility before they answer any of your interview questions, especially if the questions are more personal in any way. For example, provide the subject with links to other interviews you have administered by email and published on the Internet, or any of your work that you think is relevant.

Make yourself available even after the study has been done, in case there is a need to follow up or give the participants feedback. Use different means for your participants to reach you if desired, not only via email but also by phone call or face-to-face interaction.

Please note that this chapter does not present or discuss ways to analyze the information gathered or issues of anonymity and confidentiality of your participants. Nonetheless, we offer the following session to contextualize the use of email as a research tool within a brief study on aging involving older adults, and we may refer to analysis and confidentiality to illustrate a point or two.

4 Our Experience in Using Email as an Interview Tool

Given the nine-step process above, we now provide you with a critical evaluation of email as a research tool within a qualitative pilot study of feelings and experiences associated with aging as published elsewhere (and adapted in here from Brondani

et al. 2010). The participants we encountered, an Italian-speaking man and a Portuguese-speaking woman, offered to participate only if we would communicate with them solely by email; we had not planned to use such a venue initially. After obtaining ethical approval from the University of British Columbia's Office of Research Services, we had a face-to-face meeting on obtaining signatures for informed consent (you do not necessarily need to do this). We then proceeded to communicate electronically with the two participants. Throughout that process, we observed several salient issues as presented below.

4.1 Delayed Responses and Absence of Punctuation

Most of the information was exchanged in a "received and answered format." Although there was no mandatory deadline for a reply or response (which we should have established), we received their responses within 72 h, as is suggested in the literature as sufficient time for a thoughtful reflection and response (McAuliffe 2003; Meho 2006).

Although punctuation is regarded as either a representation of a spoken word to convey intonation, duration, or stress or an integral part of the syntax, both participants emailed us back with responses using irregular or random absence of grammatical punctuation: either commas or periods. The absence of grammatical pauses is not uncommon within an online environment such as instant messenger and text services, particularly commas and full-stops when space is limited or cost per text is an issue. Even though such apparent freedom in punctuation rules can confuse the meaning of a sentence, the informality and ease of interactions make it relatively easy for us to seek clarification when needed (Flowers and Moore 2003; Meho 2006). More often than not, punctuation is avoided at best, or misplaced at worst, in transcribed texts from regular face-to-face interactions to the extent that free software (Ginger[®] Software) and statistical methods have been proposed to assert that the text is correctly punctuated (O'Kane et al. 1994). However, third-party initiatives like these can unintentionally change the meaning of what was originally conveyed, or change the significance of an entire sentence. Either way, it remains in the interpretation of the individual analyzing the textual information to make sense of sentences or excerpts given the context in which they occur.

4.2 Indirect Contact and Body Language

Forget about human interaction. There is a standardized online conversational behavior called "Netiquette" among most Internet users that substitutes paralinguistic cues and nonlinguistic body language with specific symbols to express feelings, emotions, and sentiments. For example: "🙂" indicates a happy face; "😉" indicates a wink; and "lol" indicates a laugh-out-loud (King 1996; Selwyn and Robson 1998; McAuliffe 2003; Shea 2004). In fact, there has been a proliferation of emoticons (An *emoticon*, "etymologically a portmanteau of emotion and icon, is a metacommunicative

pictorial representation of a facial expression that, in the absence of body language and prosody, serves to draw a receiver's attention to the tenor or temper of a sender's nominal nonverbal communication, changing and improving its interpretation." (Wikipedia)) available in *smartphones* and in almost any online communication (Wikipedia 2015); they even became a movie in 2017 - The Emji Movie by Sony Pictures Animation. Our two participants seemed comfortable with the focus of our enquiries, and, with no hint of distress or difficulty, occasionally used the symbols to tell their stories more emphatically. Apparently, we created an easy, trusting, and friendly relationship as evidenced by the informality and general tone of our exchanges. This easiness in online communication has also been documented by others (Melenhorst and Bouwhuis 2004; Reisenwitz et al. 2007).

Despite the availability of symbols to express emotions and compensate for the lack of visible body language, email as a one-dimensional textual data continues to pose limitations on the detection and interpretation of emotions (Haythornthwaite 2000), especially if that is a part integrant of, or informant to, the research being conducted. High-resolution web cameras with voice and video capabilities would probably help to overcome these limitations. In addition, it can be difficult for interviewers to acquire the skills needed to probe for responses when the emotional environment of direct human contact is missing (Flowers and Moore 2003).

4.3 Validation

The validation of qualitative data obtained by face-to-face interviews usually occurs while probing the participants during the interview, or later, through *member checks* (Liamputtong 2013; Creswell 2014). Despite the challenges in establishing or even in actually needing member checks, we argue that the same validation could happen for electronic interviewing. In turn, the informality of the interactions offered us the opportunity to validate and enhance the trustworthiness of data analysis as communications continued (Meho 2006). It should also offer the benefit of being able to easily prompt participants to express further feelings, thoughts and perceptions; it also increases rapport between the interviewer and participant (Patton 2015). Similar to either electronic or in-person interaction, it may be difficult for some participants to respond adequately if the question posed is too short, ambiguous, or unnecessarily succinct and they do not understand it as we have originally planned. Due to the informality of electronic communication, however, we are easily able to provide clarification as often as needed, and to gather the most information from the electronic interaction.

4.4 Informality

It has been suggested that email provides a context for a noncoercive and anti-hierarchical dialogue to promote equal opportunity and reciprocity (Brondani et al. 2010), which constitutes an ideal situation free of internal or external intimidation

(Creswell 2014). From the beginning, our participants adopted informal language when greeting the interviewer. When asked about what a normal day looks like to them, for example, they embellished their responses: “... *my day is really good (and I tell you... it is a way better than I thought it would be)* ...,” and “*first, I have my cappuccino around 8:00 in the morning ... well, actually the coffee here is not as good as in the village where I used to live, but ...*” (adapted from Brondani et al. 2010). These spontaneous expressions provided information similar to that which one would expect on a face-to-face context (Patton 2015), as off-topic comment, or as a way to embellish their remarks.

4.5 Sampling Possibilities and Cost-Effectiveness

E-communication opens up the possibility of sampling on a very large scale globally with relatively low administrative costs (Selwyn and Robson 1998; Harwood 2007; Hackworth and Kunz 2010). It potentially mitigates conventional constraints of spatial and temporal proximity between interviewer and subject, and offers the possibility of a relatively unobtrusive and communicative environment. There is less concern for social hierarchy, and it may decrease the uneasiness caused by a dominant interviewer confronting a shy respondent, or a young interviewer with an elderly subject (Selwyn and Robson 1998; Etter and Perneger 2001). This may be especially relevant when engaging with marginalized and vulnerable participants when a power relationship becomes an issue (Cook 2012; Neville et al. 2015).

There is clear cost-effectiveness from e-interviews because they provide written information directly without the costs of transcribing oral interviews and the textual data is ready to be analyzed (Flowers and Moore 2003). Furthermore, email interviews eliminate the need for tape-recorders and audiotapes, and for specific time, place and travel arrangement, which are required when conducting face-to-face interviews.

Although our participants themselves offered the use of emails, response rates to structured surveys in general have declined over the last few years, either paper format or online (Funkhouser et al. 2014). However, the response rates are also related to the size of the population under study – larger populations require smaller response rates (Nulty 2008) and in the case of a qualitative inquiry, sample size is not a major issue (Liamputtong 2013). In particular, response rates to online surveys about oral health are within the range of 2.5–26% (Goodchild and Donaldson 2011; Henry et al. 2012). Methods for boosting online survey response rates would include extending the period of data collection, repeat reminder emails to nonrespondents, repeat reminder emails to survey owners/coordinators, providing incentives for respondents, and optimizing the use of online environments by utilizing online teaching aids/methods for examples (Nulty 2008). Of note is to make sure that your participants can actually type on a key board or use dictation software and speech recognition tools when physical limitation and dexterity are issues to be considered, which may be the case depending on the nature of your research or target group of participants.

4.6 Conclusion and Future Directions

This chapter aimed at presenting the pros and cons of using email as an example of Internet-based communication application for collecting qualitative research data and information. We first offered a nine-step process on how to administer an electronic interview, and we then discussed the advantages and disadvantages of such means while drawing from a brief experience in using email to interview older adults for a research study on aging. We now invite the reader to ponder about the use of email in today's exploratory and always evolving research arena as an alternative means to conference calls or face-to-face interviews when time and resources are restricted. There is no question that email as a research tool can be of value. Although misspelling and the lack of punctuation may delay prompt interpretation of the responses, the use of emails as illustrated by our brief study seems to be useful and effective when collecting information from participants who are comfortable with this form of communication. Nonetheless, there is a need for further studies to support, refute, or illuminate these findings.

In all, we believe that email has potential to be a data collection tool since it:

- eliminates the constraints of time and space
- offers cost-effectiveness by eliminating the need for tape recorders, transcription machines, and transcripts
- offers already transcribed textual data
- provides a noncoercive and antihierarchical dialogue enhancing equal opportunity and reciprocity
- may increase response rates

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Cell Phone Survey

80

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Contents

1	Cellphones in Health Survey Research	1404
2	Methods of Constructing “Dual Frame” Surveys	1405
3	Methodological Considerations When Using Cell Phone Sampling Frames	1407
3.1	Noncoverage Bias	1408
3.2	Nonresponse Bias	1410
3.3	Cost-Efficiency and Feasibility of Cell Phone Surveys	1412
4	Conclusion and Future Directions	1413
	References	1413

Abstract

The global rise in cell phones usage has undermined traditional data collection modes, notably landline surveys, and has elicited the development of novel survey methods and designs. Adopting a single landline frame survey is no longer viable, owing to its undesirable implications on response rate, coverage, as well as data representativeness and validity. Subsequently, researchers have developed methods to integrate the cell phone and landline frames, and conduct “dual frame” surveys using either overlapping or nonoverlapping modes of integration. Dual frame surveys have gained popularity as they were shown to enhance the quality of the collected data and improve the validity of national estimates. Of course, cell phone surveys, be it single frame or dual frame, are not void of methodological challenges relevant to sampling frames, participant selection, respondent burden, and collection of reliable and valid data. The evidence concerning the proper implementation of cell phone surveys, as well as the feasibility of a single frame cell phone survey is relatively recent especially

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when youth are the targeted population. Given their proliferation worldwide and the diminishing existing barriers, cell phones are expected to become an inevitable mode for collecting health survey data. Yet, the need remains for contextualizing their feasibility as per each country's settings and circumstances.

Keywords

Cell phones · Telephone · Bias epidemiology · Validity · Feasibility

1 Cellphones in Health Survey Research

Face-to-face and landline telephone interviews have been the most common data collection methods in health survey research (Nelson et al. 2003; Schofield and Forrester-Knauss 2017; see also ► [Chap. 32, “Traditional Survey and Questionnaire Platforms”](#)). Face-to-face interviews allow the collection of more detailed information on a wider range of topics (Nelson et al. 2003) and have better response rates (Massey et al. 1997), but they are more costly and time consuming than landline telephone interviews. The latter also allow researchers to reach out to a larger pool of respondents (Anie et al. 1996; Aziz and Kenford 2004) and reduce methodological issues by reducing social desirability, providing greater anonymity (Babor et al. 1990; Schwarz et al. 1991) and minimizing the influence of other household members (Anie et al. 1996).

The traditional landline telephone interviews have been recently challenged by the rise of new communication technologies, namely mobile phones, which have since been used for the collection of health and nonhealth-related survey data (Brick et al. 2007a; Ekman and Litton 2007; Vehovar et al. 2010). Globally, in high as well as low and middle income countries, an increasing number of people have switched to mobile phone use only, reducing the number of households with landline phones (Blumberg and Luke 2014; Liu et al. 2011; McBride et al. 2012). In the United States (USA), nearly 41% of American homes, and particularly two third of adults aged 25–29 years old, do not own a landline telephone (Blumberg and Luke 2014). The World Bank estimates that mobile phone subscriptions grew 40-fold from 1997 (2%) to 2011 (85%) and have either exceeded or are approaching 100% in both developed and developing countries (multiple cell phone lines per subscriber), such as Finland (166%), Italy (158%), Argentina (135%), Bulgaria (141%), Kuwait (175%), Bahrain (128%), Jordan (118%), and Egypt (101%) (World Bank 2013).

The rise in cell phone usage and the number of households that can be solely reached by mobile phones has undermined data collection using landline telephone surveys, specifically through reducing the completeness of the landline phone directories (Blumberg and Luke 2010). From an epidemiological standpoint, this impacts the coverage of landline only phone surveys, and the quality of the data derived using this method (Kempf and Remington 2007; Link et al. 2007; Hu et al. 2010). To elaborate, sampling frames that exclude members or groups of the target population raise concerns that those missing may be different from those included, hence threatening the representativeness of the sample (Lee et al. 2012) and resulting

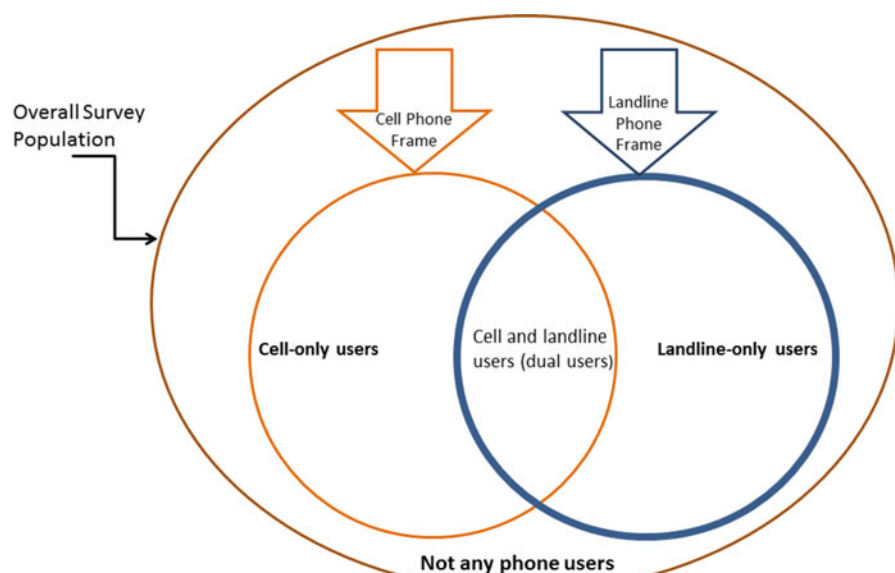
in biased survey estimates, whether health prevalence statistics (Keeter et al. 2007; Blumberg and Luke 2009; Baffour et al. 2016), data on lifestyle behaviors (Ehlen and Ehlen 2007), or data on political attitudes (Keeter et al. 2008).

The rapid increase in wireless phone usage, particularly among the young (Keeter et al. 2007), has rendered landline only surveys not only inaccurate for provision of national data (Lee et al. 2010) but also increasingly inadequate in capturing hard-to-reach young populations (Gundersen et al. 2014). For example, the exclusion of mobile phones from the 2007 CDC Behavioral Risk Factor Surveillance System (BRFSS) in the USA resulted in lower estimates of binge drinking and smoking among young adults (Blumberg and Luke 2009) when compared to those from the household face-to-face National Health Interview Survey (NHIS) (Delnevo et al. 2008). Attempting to address these differences in estimates by weighting methods that adjust for the proportionality of a certain group is not an option, as noncoverage bias is the product of both the degree of noncoverage and differentials between respondents and nonrespondents (Lesser and Kalsbeek 1992). Thus, it has become necessary to integrate cellphone users in landline telephone survey sampling frames.

2 Methods of Constructing “Dual Frame” Surveys

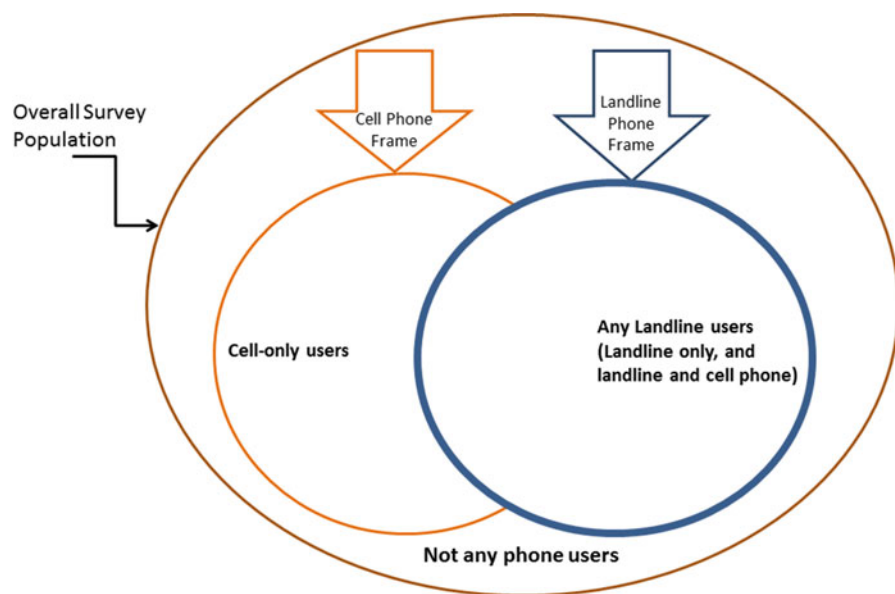
Surveys integrating landline and cellphone users are labeled “dual frame” or “dual-mode” surveys. Dual-mode surveys are feasible but are not void of challenges that are mainly logistical in nature (Brick et al. 2007a, b; Link et al. 2007). There are at least two approaches to integrating mobile phone numbers into landline telephones surveys. One approach uses an overlapping design whereby the two sampling frames are combined (Fig. 1). Such a design requires the availability of two sampling frames, the first including all the residential landline phone numbers and the second all the cell phones numbers; the use of Random Digit Dialing (RDD) for the selection of phone numbers ensures that all phone numbers have equal chances of being selected (The American Association for Public Opinion Research 2010). Obviously, dual users, or households with access to both landline and cell phones, will have a higher chance of being selected, and adjustment for this dual frame multiplicity will follow by composite weighting procedures to generate unbiased results (Blumberg et al. 2009; Best 2010). Such weighting procedures are different for each country, as they are benchmarked against variations in phones distribution in the population (landline only, landline and cell phone, and cell phone only) (The American Association for Public Opinion Research 2010; Barr et al. 2014a). While overlapping frames require a complex weighting strategy, this approach has been particularly favored in risk factor surveillance systems and chronic disease surveys (Hu et al. 2011; Barr et al. 2012; Livingston et al. 2013; Jackson et al. 2014).

Another approach is the nonoverlapping design, better known as the screening dual frame design (Fig. 2). This entails screening the mobile phone sampling frame to select the cell-only users and removing the duplicated units (households with both a landline and cellphone(s)) from the mobile phone sampling frame. This would result in a sampling frame consisting of two separate strata (the mobile only users



Adapted from: Elkasabi MA. Weighting procedures for dual frame telephone surveys: a case study in Egypt. Survey Methods: Insights from the Field (SMIF); 2015. <http://surveyinsights.org/?p=5291>

Fig. 1 The overlapping design in a dual frame telephone survey



Adapted from: Elkasabi MA. Weighting procedures for dual frame telephone surveys: a case study in Egypt. Survey Methods: Insights from the Field (SMIF); 2015. <http://surveyinsights.org/?p=5291>

Fig. 2 The dual screening design in a dual frame telephone survey

and landline users), with sampling being comparable to stratified random sample design. The screening process can only be done during data collection, rendering the nonoverlapping design more costly than the overlapping design (The American Association for Public Opinion Research 2010).

Researchers took more interest in the overlapping design as it can result in estimates based on four comparison groups: landline only and landline-cell phone users sampled from landline frame, as well as cell phone only and cell phone-landline users sampled from cell phone frame. As aforementioned, this design has become increasingly popular, notably in national health surveys in Australia (Barr et al. 2014a, b).

Of relevance to integrating mobile phone numbers into telephone surveys is obviously identifying or creating a cell phone sampling frame, which is not as straight forward as a traditional landline sampling frame (Kempf and Remington 2007). In contrast to landline surveys, a cell phone respondent does not represent households, as cell phones are attached to individuals rather than a geographic location leading to further statistical and operational implications (Link et al. 2007). Another major challenge is the issue of establishing the eligibility of the respondent in mobile phone surveys (Brick et al. 2007a; Moura et al. 2011; McBride et al. 2012; Gundersen et al. 2014). This is particularly problematic when call receivers are below 18 years of age (Call et al. 2011) or when they refuse to confirm their age even after the study protocol and the importance of excluding minors from the survey has been clearly explained (McBride et al. 2012). Therefore, the likelihood of rechanneling the call to an eligible subject in landline phone interview is higher (Brick et al. 2007a). Issues of eligibility extend also to cases when the cell phone number is linked to fax machines, business phones, or wireless cards assigned for computers and tablets (Gundersen et al. 2014).

Typically, an assumption is made that cell phones are personal and not shared household devices, meaning there is one-to-one correspondence between the person answering the cellphone and the household (Link et al. 2007). However, cell phone sharing may still be common in various forms (e.g., shared one third of the time, shared half the time), adding to the complexity of establishing whether the cell phone is “shared” or not (Busse and Fuchs 2013). In fact, little and inconsistent evidence on cell phone sharing exists (Brick et al. 2007b; Carley-Baxter et al. 2010; The American Association for Public Opinion Research 2010), and interviewers may need to ask some questions to make sure that the household has not been previously contacted.

3 Methodological Considerations When Using Cell Phone Sampling Frames

Household surveys using face-to-face interviews have been viewed as the gold standard in terms of obtaining national estimates, and other modes of data collection have been consequently compared against them (De Leeuw 2008; Delnevo et al. 2008). In contrast to the relatively good number of studies providing evidence on the agreement in disease and risk factor prevalence rates from landline interviews

Table 1 Agreement (Kappa Statistics) between data obtained from a cell phone survey ($N = 630$) versus a face-to-face interview ($N = 630$): Data from Lebanon collected as part of the Nutrition and Non-communicable Disease Risk Factor Survey nationwide cross-sectional population-based household survey, 2009 (Mahfoud et al. 2015)

Variable	Face-to-face interviews ($N = 630$)		Cell phone survey ($N = 630$)		% Agreement	Kappa statistics
	n	%	n	%		
Current cigarette smoking	245	38.9	239	37.9	95.6	0.91
Reported diabetes	48	7.6	43	6.8	98.3	0.87
Having health insurance	388	61.6	391	62.1	92.2	0.84
Past year alcohol consumption	299	47.5	307	48.7	89.5	0.79
Current waterpipe smoking	159	25.2	170	27.0	91.3	0.77
Reported hypertension	76	12.1	85	13.5	92.9	0.68
Reported heart disease	25	4.0	36	5.7	97	0.67
Reported hyperlipidemia	94	14.9	79	12.5	91.9	0.66

compared to population-based face-to-face interviews (Groves and Kahn 1979; Herzog et al. 1983; Herzog and Rodgers 1988), studies comparing cell phone to face-to-face interviews remain scarce. Mahfoud et al. (2015) examined the reliability of self-reported responses generated by cell phone interviews and face-to-face interviews and observed very high concordance (kappa statistics >0.8) for outcomes such as cigarette smoking and diabetes, as well as substantial agreement ($0.6 < k < 0.8$) for other measures such as water pipe smoking, alcohol consumption, and hypertension (Table 1). The high reliability alleviates concerns on how to handle dual users, in terms of selection and weighting procedures, in dual frame surveys (The American Association for Public Opinion Research 2010).

Overall, the validity and reliability of data obtained from surveys can be compromised by one or more factors including selection of sampling frames, design effect, response rates, and interviewing techniques (Kempf and Remington 2007). Dual frame surveys (e.g., cellphone and landlines) and mixed mode surveys (e.g., face-to-face, phone interviews, and online forms of data collection) may alleviate bias, but they face other challenges such as bias due to mode effects (when the multiple interviews methods used for a single survey influence respondent answers) (Lugtig et al. 2011). When integrating cell phones into phone surveys, an assumption is made that this enhances representativeness and that the data derived from cell phone interviews are both reliable and valid. Below, we cover the main epidemiological biases in cell phone surveys and, when available, methods that have been used to mitigate them or reduce undesirable effects on data quality.

3.1 Noncoverage Bias

The substantial differences between landline and mobile only users that have been found in cross-sectional and longitudinal study designs and in developmental and

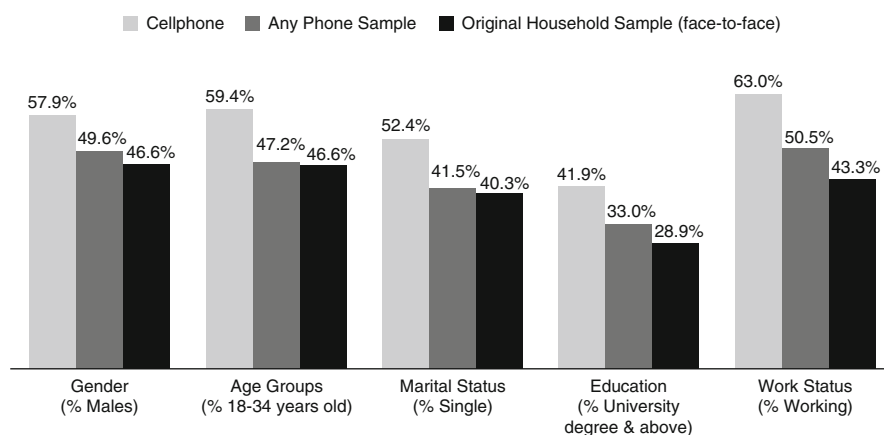


Fig. 3 Comparison of sociodemographic characteristics of cell phone sample ($N = 1381$), any phone sample ($N = 2126$), and face-to-face sample ($N = 2656$); Data from Lebanon collected as part of the Nutrition and Non-communicable Disease Risk Factor Survey nationwide cross-sectional population-based household survey, 2009 (Sibai et al. 2016)

applied research as well (Jackson et al. 2014) necessitate the inclusion of cell phone only users into traditional phone sampling frames. Several studies have noted differences in sociodemographic characteristics, whereby cell phone only users were more likely to be young, males, speak English, to live in rented homes, and to belong to certain ethnicities with low socioeconomic backgrounds than the general population (Blumberg and Luke 2007; Dal Grande and Taylor 2010; Lee et al. 2010, 2012). In other studies, cell phone respondents have also reported higher educational level (Dal Grande and Taylor 2010; Lee et al. 2012). Worth noting is that the evidence has been mostly from the West, with very little data from the less-developed world. One study from Lebanon in the Middle East further stresses these marked differences, showing that cell phones users (irrespective of whether they belong to households with or without landlines) were more likely be male, young, single, of a higher educational level, and part of the labor force (Fig. 3; Sibai et al. 2016).

Differences have also been noted in risk behavior estimates. Compared to landline users, studies have shown that cell phone users (whether cell phone only population, or dual users) have higher rates of heavy drinking; smoking; and risky sexual behavior (Blumberg and Luke 2009; Dal Grande and Taylor 2010); illegal drug use and gambling problems, notably among the young (Barr et al. 2012, 2014a; Livingston et al. 2013); as well as poorer mental well-being and higher incidence of psychological distress (Baffour et al. 2016). Other studies have shown that lying about gambling behavior and attempts to control gambling behavior were significantly more likely to occur within the mobile sample (Jackson et al. 2014), even if compared within the same age category (Keeter et al. 2007). Nonetheless, recent data from the household-based Australian National Health survey showed that mobile-only users were more physically active and had lower prevalence of obesity compared to landline accessible population (Baffour et al. 2016).

Adjustment for age, gender, and geographic location, among other factors responsible for noncoverage and nonresponse, tend to lessen differences in health indicators and prevalence estimates between both landline and cellphone frames (Lee et al. 2010; Hu et al. 2011; Sibai et al. 2016). Nonetheless, adjustment is not sufficient to justify the exclusion of cell phone only users from sampling frames. Hu and colleagues demonstrated the remaining potential noncoverage bias when excluding cell phone only users for 16 health-related outcomes (most notably in the context of alcohol consumption among adults), even after adjustment for demographic differences (Hu et al. 2010). Barr (2008) estimates that, in Australia, when landline phone users drop to below 85%, the difference in health indicators between landline owners only and cell phone users only will become significant and will impact national health statistics.

To sum up, the exclusion of cell phone sampling frame will impact the validity of the survey findings by reducing representativeness of the study. Adjustment for demographic characteristics is unlikely to totally resolve the noncoverage bias issues consequent to its omission.

Taking it a step further, in countries with high penetration rate of cellphone within certain age groups, researchers have benchmarked the quality of data collected solely through a cell phone frame against a national survey that included both landline and cell phone or landline only. As an example, findings on the prevalence of cigarette smoking among young adults aged 18–34 years old were not significantly different between the National Young Adult Health Survey (NYAHS) based on cell phone frame compared to data collected from the BRFSS based on dual frame sampling for the same age group (Gundersen et al. 2014). Similarly, a sexual youth survey targeting women 18–39 years old from Australia reported no differences on almost all variables, including demographic and health-related outcomes between the two sampling frames (Liu et al. 2011). Therefore, the future of having a single sampling frame seems feasible under certain conditions and will tend to reduce the time-length of the survey and the cost per interview, especially that questions related to ownership of telephones would not be needed anymore (Liu et al. 2011; Guterbock et al. 2013; Gundersen et al. 2014).

3.2 Nonresponse Bias

Besides sampling challenges, telephone surveys are increasingly affected by decreasing response rates (Curtin et al. 2005; Carley-Baxter et al. 2010; see also ► Chap. 81, “Phone Surveys: Introductions and Response Rates”). Compared to landline telephone surveys, mobile phone surveys are challenged by lower response rates, higher refusal rates, and lower refusal conversion rates (Steeh 2004; Brick et al. 2007a). The 2010 Irish Contraception and Crisis Pregnancy survey (ICCP) found that an overall higher percentage of valid telephone numbers go unanswered after ten contact attempts for the mobile telephone strand (30%) compared to the landline telephone strand (24%) (McBride et al. 2012). Subsequently, lower response rates will occur in the mobile strand as illustrated in the New South Wale Population

Health survey (31.5% vs. 35.1%) (Barr et al. 2012), the gambling behavior survey in Australia (12.7% vs. 22.2%) (Jackson et al. 2014), and in various other surveys across the USA including New Mexico (31.3% vs. 51.9%) and Pennsylvania (23.2% vs. 45.3%) (Link et al. 2007), as well as in the 2011 BRFSS (27.9% vs. 53.0%) (Gundersen et al. 2014).

Factors affecting cooperation and response rates in cell phone surveys are mostly “situational,” related to the circumstances in which the respondent had received the call (e.g., at work, shopping, or driving) and less so survey-related (e.g., the topic of the survey) (Brick et al. 2007b; Carley-Baxter et al. 2010). The call is likely to be perceived as a burden by the respondents who may be simultaneously engaged and constrained in other activities when receiving the call, subsequently affecting response rate (Lavrakas et al. 2007). Response rates are also likely to be influenced by the country-specific cell phone charges policy. Mahfoud et al. (2015), for example, reported a relatively high response rate for cellphone interviews (82%), attributing this to the fact that receiving cell phone calls in Lebanon is free of charge. Incentives also play a role. For example, comparing a 10\$ to a 5\$ incentive leads to higher response rates for the higher incentive provided (25.8% vs. 18.6%) (Brick et al. 2007a). Still, and even with no incentives, McBride et al. (2012) noted “a high-unusual” response rate for both the cell phone (61%) and landline interviews (79%) in the 2010 ICCP survey, accredited to using a telephone system with a blocker caller ID to evade potential back calls that would have entailed additional costs on behalf of the respondents. Of course, mobile telephone owners may be more reluctant to answer a blocked Caller ID or may also become irritated at receiving “missed” calls from an unknown source on their personal mobile phone. Alternatively, respondents may be provided with a toll free hotline or a link to the Institutional Research Ethics Committee and their contact details (Hu et al. 2011; McBride et al. 2012).

One method that has been employed to increase response rates is the refusal conversation procedure through recontacting respondents who refused to participate in the survey upon first contact one final time, giving them an opportunity to reconsider their decision or by scheduling an appointment for the interview (e.g., when incoming calls would not incur a cost on the respondent, or at a more convenient time) (Hu et al. 2011). While interviewers of the BRFSS relied on such a procedure to increase response rates in the cell phone strand (Hu et al. 2011), McBride opted for not using this method halfway through the survey as it resulted in annoyance of respondents (McBride et al. 2012). Often, phone respondents are irritated and inquire about how their telephone numbers were obtained. As such, interviewers will need to stress the importance of surveys for the public good and to explain to the interviewees the principles of RDD and assure that mobile telephone numbers are not being purchased from a database or other external sources (McBride et al. 2012) (see also ► Chap. 81, “Phone Surveys: Introductions and Response Rates”).

Regardless of methods to enhance response rates, it is important to note that there are different formulas to calculate survey response rates, which may partially explain these observed variations across studies (The American Association for Public Opinion Research 2011).

3.3 Cost-Efficiency and Feasibility of Cell Phone Surveys

One major drawback mentioned in different studies using mobile frames, with or without a landline frame, is the cost incurred to obtain complete interview data, since cell phone numbers typically need to be contacted more often than landlines to establish a final contact or to reconnect after having lost network coverage in the middle of the call (Kuusela et al. 2008; Jackson et al. 2014; Barr et al. 2012).

Some researchers have argued that cell phone surveys are impractical in certain contexts such as in the USA, China, and Canada, where mobile phone surveys induce a cost for the respondent if they are accessing a mobile network other than their service provider (i.e., roaming) or on a prepaid plan that charges for incoming calls (Link et al. 2007; Vehovar et al. 2010; Hu et al. 2011).

Furthermore, additional screening and hence a higher cost is entailed when the study protocol targets subjects based on dual frames whereby longer screening protocols are needed (in contrast to single frames) (Keeter et al. 2007; Gundersen et al. 2014). The evidence has however varied depending on the study context as well as study protocol and design. In the first dual frame survey in Brazil, the cost of cell phone interviewing was 6.6 times that of landline survey, making it inconvenient at the time of the survey (Moura et al. 2011). In the New South Wales Population Health survey in Australia, mobile frames cost was only 2.3 times more than landline frames, rendering the inclusion of a cell phone group manageable (Barr et al. 2012). In the 2007 BRFSS conducted in three states, Pennsylvania, New Mexico, and Georgia, the cost of one complete landline survey interview was approximately 64 USD, increasing to 74 USD for a cell phone survey interview, and approaching 196 USD, when there was the need to screen and select cell phone-only users (Link et al. 2007). Guterbock and colleagues (2013) estimated that cell phone interviews cost overall 50% more than landline phone interviews. Nonetheless, cell phone interviews may still be appealing, useful, and affordable in countries and regions of conflict where access to certain geographical areas is physically challenging and landline interviews are difficult to conduct in the case of mobile population (Sibai et al. 2016).

Contrary to the landline interviews, scheduling calls for cell phone interviews are equally convenient across different time periods, whether on weekdays or during weekends (Brick et al. 2007a). There is no need to worry about the optimal time of the day to contact respondents as the vast majority keep their cell phone turned on all the time (Carley-Baxter et al. 2010). However, as mentioned earlier, cell phone interviews can reach individuals in circumstances that may not be ideal for them to respond to the call or to be fully engaged in the interview (e.g., while shopping). In one study from the USA, it was found that while 56% of mobile phone respondents were at home when undertaking the survey, an additional 14% were driving, 13% were at work, and the others were in public spaces, on holidays, visiting friends and relatives (Brick et al. 2007a). The question of being “fully and cognitively engaged” in the interview process without being distracted by other activities clearly impacts overall data quality (Link et al. 2007). To address these issues, interviewers need to be instructed to be proactive and pick up cues as to whether the respondent might not

be in a position to answer the survey and to offer the respondent a callback at a more convenient time (Brick et al. 2007a; Hu et al. 2011; McBride et al. 2012).

Cellphone surveys may need to be shorter than those conducted via landline telephones to ensure high data quality (Lavrakas et al. 2007). Also, there is the issue of privacy that may entail legal consequences and be problematic in some countries where calling private mobile telephones may breach communication legislation and consumer protection acts (Kempf and Remington 2007; Lavrakas et al. 2007; McBride et al. 2012).

4 Conclusion and Future Directions

Cell phone coverage is increasing globally, rendering the use of cell phones a necessity rather than a choice, in order to obtain representative and valid estimates (Link et al. 2007). Yet, it remains imperative to construct or identify, and evaluate both landline and mobile sampling frames before conducting phone surveys to ensure adequate coverage. There is also no “best buy” to sampling mobile phone users; researchers must consider multiple factors, including the survey budget, typical country participation and response rates, as well as legal issues (Kempf and Remington 2007). The use of a mobile phone frame to obtain national data has been deemed proper if particular segments of the population are targeted, such as young adults (Liu et al. 2011; Gundersen et al. 2014). However, published literature still lacks solid and empirical evidence regarding reliability and feasibility of cell phone only as well as dual frame surveys from the middle- and low-income countries, necessitating further contextual research in this field. In the near future, it is expected that the implementation of mobile surveys will become less complex owing to the reduction of existing barriers, prompting researchers to move forward by adopting them, with or without other modes of data collection.

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Phone Surveys: Introductions and Response Rates

81

Jessica Broome

Contents

1	The Relationship Between Interviewer Speech and Vocal Characteristics and Success ..	1418
2	A Model of Interviewer Voice and Speech to Minimize Nonresponse	1420
3	Green Lights and Red Flags	1423
4	Recommendations for Telephone Interviewing Practice	1425
4.1	Recommendation #1: Train Interviewers to Switch Gears from Conversational Introductions to Standardized Interviews	1426
4.2	Recommendation #2: Train Interviewer Speech Rates; Consider Implementing Hiring Criteria around Vocal Pitch	1427
4.3	Recommendation #3: Emphasize Responsiveness to Answerer Concerns	1427
4.4	Recommendation #4: Train Interviewers to be Aware of and Respond to both “Red Flags” and “Green Lights” from Answerers	1427
5	Conclusion and Future Directions	1428
	References	1429

Abstract

As web surveys increase in popularity, the focus in the research industry on telephone surveys continues to decline. However, phone surveys are far from becoming extinct. Limited Internet access among certain populations (including older and lower income groups) makes telephone a preferred methodology when broad cross-sections of a population need to be reached, such as in the health research arena, where large-scale surveys such as the Behavior Risk Factor Surveillance System (BRFS), California Health Interview Survey (CHIS), and the Canadian Community Health Survey (CCHS) rely on telephone surveys. An understudied but critical component of phone surveys is the introduction.

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Introductions that are effective at convincing sample members to participate can help to improve shrinking response rates in this mode. These declining response rates have the potential to contribute to nonresponse error, and interviewers contribute differentially to nonresponse. Why do some telephone interviewers have better response rates than others? What are key speech and vocal characteristics of interviewers that help their performance, and how can these characteristics be implemented in practice? This chapter will review existing literature on telephone survey introductions, examine components of an ideal introduction, and conclude with suggestions for effective interviewer training in this area.

Keywords

Telephone · Interviewer · Nonresponse · Response rates · Survey · Voice · Speech

1 The Relationship Between Interviewer Speech and Vocal Characteristics and Success

Nonresponse to telephone surveys has been increasing steadily over the past 25 years (Curtin et al. 2005), and declining response rates have the potential to increase nonresponse error (Teitler et al. 2003; Groves et al. 2004; see also ► Chaps. 32, “Traditional Survey and Questionnaire Platforms” and ► 80, “Cell Phone Survey”). Further, nonresponse rates vary by interviewer (Oksenberg and Cannell 1988; Morton-Williams 1993; O’Muirheartaigh and Campanelli 1999; Snijders et al. 1999). Uncovering the characteristics and tactics of successful interviewers can help to reduce nonresponse, either by using vocal and personality characteristics as hiring criteria or by training interviewers to adopt characteristics or tactics which have been shown to lead to increased success.

Literature from both survey methodology (Oksenberg et al. 1986) and telemarketing (Ketrow 1990) has found that a pleasing or attractive voice in the initial seconds of a phone call is imperative in extending the interaction. Further, Ketrow (1990) discusses the importance of giving an initial impression of competence, and Oksenberg and colleagues (Oksenberg et al. 1986; Oksenberg and Cannell 1988) found that judges’ ratings of phone interviewer competence based on brief recorded excerpts were positively associated with the interviewers’ success. This is not to imply that, in survey interview introductions, having a pleasing, competent-sounding voice in the opening statement is enough to guarantee success. However, an interviewer voice that gives listeners a positive first impression may lead to a longer conversation, thus increasing the likelihood of participation.

In contrast to face-to-face interviewers, telephone survey interviewers have just two primary tools which are under their control in their efforts to persuade answerers to participate: what they say (speech) and how they say it (vocal characteristics). A small body of literature (e.g., Sharf and Lehman 1984; Oksenberg et al. 1986; Oksenberg and Cannell 1988; Groves et al. 2007; Conrad et al. 2013) finds relationships between vocal characteristics of interviewers in telephone survey introductions and interviewer success in obtaining interviews. In general, successful interviewers

have been ones who spoke louder (Oksenberg et al. 1986; Oksenberg and Cannell 1988; Van der Vaart et al. 2005) and with more falling intonation (Sharf and Lehman 1984; Oksenberg and Cannell 1988). In addition, success has been shown to be correlated both with higher mean fundamental frequency (Sharf and Lehman 1984) and with higher perceived pitch (Oksenberg et al. 1986), as well as variable fundamental frequency (Sharf and Lehman 1984; Groves et al. 2007) and variable pitch (Oksenberg et al. 1986). The terms “pitch” and “fundamental frequency” are often used interchangeably, but a necessary distinction is that fundamental frequency is an acoustic measure of vocal chord vibrations, while pitch is a listener’s perception of frequency or how “high” or “low” a voice sounds.

Three recent studies have found nonlinear relationships between success and rate of speech (Groves et al. 2007; Steinkopf et al. 2010; Benkí et al. 2011): contacts with speech that is either overly slow or overly fast tend to be less successful. Benkí et al. (2011) found that contacts with interviewer speech in the range of 3.34–3.68 words per second were the most likely to be successful.

One critical question concerns what underlies these associations; what is it about an interviewer who speaks at a particular rate or with more variable pitch that leads to success, especially given the limited amount of exposure an answerer has to the interviewer’s voice before deciding whether or not to participate? Oksenberg et al. (1986) emphasized the importance of an interviewer having a voice that potential respondents find appealing in the first few seconds of a survey interview introduction context, stating that “if vocal characteristics lead the respondent to perceive the interviewer as unappealing, cooperation will be less likely” (p. 99).

Two dimensions of person perception, warmth and competence, have been shown across a range of contexts to be relevant to the development of first impressions of others (Asch 1946; Fiske et al. 2007). Several studies in the literature on interviewer vocal characteristics (Oksenberg et al. 1986; Van der Vaart et al. 2005) suggest that ratings of personal characteristics on these dimensions of person perception are associated with both interviewer response rates and vocal characteristics. These studies involved collecting ratings of several interviewer personality characteristics, which were then successfully reduced to two dimensions interpretable as “warmth” and “competence.” Characteristics on the “warmth” dimension included being cheerful, friendly, enthusiastic, polite, interested in her task, and pleasant to listen to. Oksenberg et al. (1986) and van der Vaart et al. (2005) found correlations between high ratings on the warmth dimension and vocal characteristics including variation in pitch, higher pitch, and a faster rate of speech, suggesting that listeners’ impressions of interviewer personality are based, at least in part, on physical (acoustic) attributes of interviewers’ voices. Characteristics composing the “competence” dimension included being self-assured, educated, intelligent, and professional. Van der Vaart et al. (2005) found that interviewers rated highly on “competence” characteristics tended to have lower pitch.

Importantly, both Oksenberg et al. (1986) and Van der Vaart et al. (2005) found that high ratings on a “warmth” dimension correlated with ratings of judges’ willingness to participate. This aligns with Morton-Williams’ (1993) finding that warm or “likable” interviewers increased perceived benefits to potential respondents and improved

participation rates and also with Cialdini's (1984) "'Liking' Principle of Compliance"; people are more likely to comply with a request from someone they like.

Further, Cialdini (1984) suggests a compliance heuristic based on the principle of authority; requests from an authoritative speaker are more likely to be honored than requests with less authority. Impressions of authoritative characteristics such as competence and confidence, in turn, have been shown to be associated with interviewer success (Oksenberg et al. 1986; Oksenberg and Cannell 1988; Steinkopf et al. 2010).

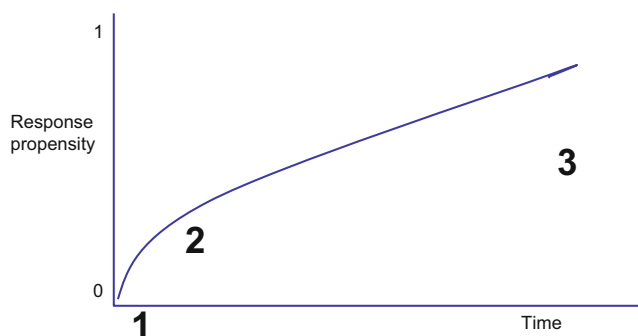
The initial impression of a phone interviewer's voice as warm and competent may offer the interviewer the proverbial "foot in the door," giving the interviewer an opportunity to tailor their introduction to be more relevant to the individual by keeping a potential respondent (hereafter referred to as a phone "answerer") on the phone longer. Groves and Couper (1998) name "prolonging interaction" as a key strategy of successful interviewers for this reason.

Interviewer responsiveness to sample members has been shown to be effective in persuasion. Campanelli et al. (1997) find that relevant interviewer responses to specific householder concerns, indicating adaptation, are a successful interviewer technique. Groves and McGonagle (2001) are able to quantify this association with their finding that interviewers' cooperation rates in telephone surveys improved after interviewers went through a training program to increase their use of tailoring techniques, specifically by focusing on giving relevant responses to concerns expressed by sample members. Similarly, Pondman (1998) finds a 49% refusal rate among interviewers who were trained in a responsive strategy (compared to a 60% refusal rate among interviewers who did not participate in the training): in response to refusals, rather than asking "why" or repeating the refusal ("You don't want to participate?"), interviewers were instructed to offer to call back if answerers indicated not having time at the moment to take part in the interview, and also to "apply the provision of relevant information about features of the interview in reaction to refusals based on reasons other than time" (p. 75).

2 A Model of Interviewer Voice and Speech to Minimize Nonresponse

Broome (2012) proposes a model (Fig. 1) which suggests that when, excluding "hard-core" nonrespondents (who would not respond no matter what an interviewer said or how she said it), an initial voice which was not scripted could get an interviewer "over the hump" of an interaction, —that is, past an immediate refusal. According to this model, after giving a positive initial impression, an interviewer who was responsive to an answerer would have more success in persuading the answerer to comply with the survey request.

One study by Broome (2015) tested the hypothesis that first impressions, formed in the initial seconds of a telephone interviewer's introduction, are critical in determining the outcome of the contact. This study used a web survey to play



- 1: Some answerers will not respond— no matter what an interviewer says or how s/he sounds.
- 2: Initial presentation of a non-scripted voice can get an interviewer “over the hump” of the interaction.
- 3: Responsiveness for the remainder of the introduction will improve response likelihood.

Fig. 1 A proposed conceptual model of interviewer behavior

recordings of a number of introductions from actual phone studies, for which the outcome was known, to listeners. The study concluded that in fact the only rating by listeners that predicted contact outcome was whether or not the interviewer sounded scripted. Ratings of friendliness, competence, confidence, and other personality traits were *not* predictive of contact outcome. But while ratings of positive personality characteristics were both unrelated to contact success, ratings of an interviewer’s scriptedness were significantly *negatively* associated with agreement, indicating that an interviewer who comes across to the listener as less scripted in the initial seconds of a contact has a greater chance of success.

While an initial impression of an interviewer as nonscripted is important, Broome (2012) also found that an interviewer’s ability to be responsive to an answerer over the course of the survey introduction is far more important to her success than any initial impression. Through coded transcripts of interviewer/answerer dialogue, Broome explored two components of interviewer responsiveness in this study. The first was whether interviewers addressed answerer concerns. Answerer utterances were coded to indicate if they contained one of thirteen specific concerns, including “bad time,” “purpose,” or “not interested.” Similarly, codes were assigned to interviewer utterances to indicate if the interviewer appropriately addressed a concern (e.g., by responding to “I’m too busy” with “We can call you back later”).

The examples below (from actual contacts) show (1) a successful interviewer attempt at responsiveness to a concern and (2) an irrelevant interviewer response to the answerer’s concern.

1. Answerer: There's a lot of questions that we probably couldn't even answer.
Interviewer: Well, it's not a test or anything.
2. Answerer: There's only two of us and my husband's in the shower and I'm in the middle of making dinner.
Interviewer: Well, this is a very important study.

Answerers may also present what Broome refers to as “conversation starters,” which are utterances that are not concerns, but that provide opportunities for interviewers to give a response that demonstrates their attentiveness. Such remarks could be phrased as either comments or questions; they could include observations about the survey task, or they could be peripheral to the task – the point is that the interviewer can respond in a way that shows she has understood and thought about the answerer's comment. As in any conversation, the interviewer can “take the bait” and acknowledge these remarks with a relevant response – what Clark and Schaefer (1989) refer to as “contributing to discourse.” Interviewers can also fail to effectively respond to answerers' conversation starters, either by offering content that is not relevant to what the answerer has said or by saying something with no substance. The example below shows a missed opportunity to respond to a conversation starter.

Answerer: The economy? I don't like it and that's the end of it.
Interviewer: Oh. Well.

Interviewers' contributions to discourse can take several forms. Examples of effective interviewer responses to conversation starters are below. In the first, the interviewer's response to the answerer's question show that she is adhering to conversational norms by answering a question addressed to her; her second turn, “Oh, thank you,” is an expression of politeness. In the second, the interviewer's response is more substantial and demonstrates attention, adaptation to the answerer's comment, and quick thinking to build rapport with the answerer:

1. Answerer: Um, this is your job right?
Interviewer: Yes sir it is.
Answerer: Oh [laughs] oh, ok well we want you to keep your job.
Interviewer: [laughs] Oh, thank you.
2. Answerer: Just so you know, the next time Nebraska plays Michigan [laughs] we're going to root for Nebraska even though you're giving us fifty bucks.
Interviewer: That's all right. I'll root for Nebraska if you do the interview. How's that?

Analyses revealed that while overall responsiveness by an interviewer is important, an interviewer's ability to address concerns trumps her responses to conversation starters in persuading an answerer to participate.

If an interviewer can keep a potential respondent on the phone long enough to engage in an exchange, responsiveness is immensely helpful. Returning to the model of interviewer behavior proposed above, Broome (2012) found that interviewers

who start out as scripted but are highly responsive as the answerer raises concerns or presents conversation starters are nearly as successful as their counterparts who begin with a low level of scriptedness and then act responsively. Thus, while being less scripted can help interviewers get past the initial “hump,” in contacts that survive the initial stage, interviewer responsiveness is crucial to success.

3 Green Lights and Red Flags

The work of an interviewer in being responsive varies greatly. Answerers who ultimately agree tend to express fewer concerns, but produce more conversation starters. In contacts that result in refusal, answerers express a relatively high number of concerns in a shorter time period and often do not give the interviewer a chance to respond. The types of tailoring opportunities (conversation starters and concerns) presented by answerers can offer the interviewer a clue as to where the contact is headed. Concerns about the purpose or content of the survey, or the length of the interview, are most common in contacts where the answerer ultimately agrees to participate, as are conversation starters (Broome 2014). This parallels the finding by Schaeffer and colleagues (2011) that when answerers ask about interview length, acceptance is more likely. This may be because concerns about call timing or survey length are relatively straightforward for interviewers to address:

1. Answerer: But you're calling at a bad time because we have company.
Interviewer: Oh, oh, I see. Is there a better time that we could call back?
2. Answerer: How many minutes is the survey?
Interviewer: It takes maybe 10 minutes. It's pretty short.

Sweeping statements of disinterest, such as “I’m not interested” or “I don’t want to participate,” and personal policies such as “I don’t do surveys,” are much harder for interviewers to respond to. These statements are the most common concern in refusals (Broome 2014); they should be viewed as red flags and handled with caution. Interviewer responses to these concerns are often ignored and followed or interrupted by hang-ups. In responding to this type of utterance, probing for more information or asking the answerer to elaborate on his or her concerns may not be an interviewer’s best strategy, as it prompts answerers to descend into a spiral of negativity. Interviewers may have a better chance of success if they treat and address “I’m not interested” as a concern in and of itself, rather than view it as a symptom of another concern.

Often, interviewers do not have a chance to address “I’m not interested” concerns: Broome found that in 26% of contacts containing an expression of disinterest, the answerer did not say anything after the statement of disinterest before hanging up, showing no willingness to react to an interviewer’s response. These statements, then, should be interpreted by interviewers as “red flags” that indicate that unless drastic action is taken, the contact is about to be terminated.

Broome found that statements of disinterest are often presented in combination with another, more easily addressable concern, and interviewers often default to addressing these concerns, rather than the answerer's lack of interest. In the following examples, the interviewer chooses to respond to other issues brought up by the answerers (repeated calls in the first example and a misunderstanding of the purpose of the call in the second):

1. Answerer: I really don't want to take it. So I need you to take me off the list or quit calling here because I don't have time to do a survey. I've already declined. They've called me like three or four times. I told them the last time that I just wasn't interested in doing it.

Interviewer: Oh, I do apologize ma'am for all the calls. We are actually coming to the end of our study and we really do need representation from your area.

2. Answerer: Yeah well I won't be interested in that. I don't even know what it's about. And then plus I'm tired of telemarketers calling here.

Interviewer: Oh I completely understand ma'am. You know a lot of times we do get confused with telemarketers. We are not telemarketers.

Interviewers may seek out an addressable concern by asking why the answerer does not want to participate as a means to establish common ground or a mutual understanding with the answerer, but Pondman (1998) found that this type of query prompts answerers to verbalize or repeat their reasons for not wanting to participate and rarely leads to conversions; interviewers at the University of Michigan are advised to "break the habit of asking what the concerns are" (J. Matuzak, March 29, 2011, personal communication). However, this is not an uncommon technique among interviewers.

It is important to note that while it is risky, asking an answerer to specify his or her concerns can be beneficial, as it sometimes prompts the answerer to express a concern that the interviewer can easily address. One technique that may be effective is following the question with a barrage of information intended to assuage myriad possible concerns, as in this example:

Answerer: Uh, you know, I'm not interested in that.

Interviewer: Ok, are there any concerns you have? This study is one of the most important studies in the country. It's looked at by the Federal Reserve Board.

Your number was chosen to represent your part of California and you really can't be replaced in the study. It's just general opinion questions.

Answerer: Ok, all right, let's do it.

Instead of probing for a specific concern, other techniques for responding to expressions of disinterest included ignoring, acknowledging, or rejecting them, as in the examples below. It cannot be said with certainty that these responses improve response likelihood; instead, they are presented as options for interviewers to consider in lieu of asking disinterested answerers to elaborate on their concerns.

Here the interviewer bypasses the answerer's statement of disinterest and moves into the household listing:

Answerer: I don't think I'm interested.

Interviewer: We can just do the first part to determine who is eligible and then after that we can just set up an appointment to call back later. It just takes 2 minutes to find out who in your household the computer will pick to participate. So what's your first name?

In the examples below, rather than ignoring the statement of disinterest, the interviewer acknowledges it directly. Faber and Mazlish (1980) suggest that acknowledging and naming negative feelings when they are expressed, rather than rejecting or downplaying them, is an effective tactic for engaging children in distress; it appears that some interviewers employ this technique with potential respondents as well:

1. Answerer: Well, I ain't interested.

Interviewer: I know you're saying you're not interested, but I'd be more than willing to talk about the study with you right now so you can familiarize yourself with it.

2. Answerer: I just don't want to do it is what it comes down to.

Interviewer: Yeah, I understand that part. Right.

Sometimes interviewers offer an explanation as to why the answerer's policy of nonresponse does not apply in this situation, as in this example:

Answerer: I just don't like to participate in phone surveys.

Interviewer: Well this is actually not a typical phone survey.

Addressing the lack of interest – that is, treating a statement of disinterest or a nonresponse policy as a legitimate and addressable concern, rather than asking answerers to elaborate on the reasons for their disinterest – may help interviewers to avoid the phenomenon discussed by Pondman (1998), where answerers who are probed to express their reasons for not wanting to participate are less likely to be converted to agreement. Other examples of rebuttals to statements of disinterest included:

1. Interviewer: Most people find this a pretty interesting study and this is really the first time it's ever been done.

2. Interviewer: A lot of people who haven't wanted to do it did participate in it and found it quite interesting.

4 Recommendations for Telephone Interviewing Practice

The findings discussed above, coupled with other findings in the survey methodology literature, have minimal use unless they can be applied to the practice of telephone interviewing to improve response rates. This section will discuss applications of these results for survey practice.

4.1 **Recommendation #1: Train Interviewers to Switch Gears from Conversational Introductions to Standardized Interviews**

The finding that judgments of an interviewer's scriptedness in the initial seconds of a contact are negatively associated with contact success should be considered by those responsible for hiring, training, and monitoring interviewers. Interviewers should be encouraged to make their speech as natural as possible, through the use of intonation patterns and word selection. Interviewers can be exposed to contacts with both high and low ratings of scriptedness to make clear the difference.

While interviewers may be required to mention particular points in their introduction or even to follow a verbatim introductory script (depending on the institution's policy), they should be trained to sound as conversational as possible, particularly at the start of their introduction. Both Houtkoop-Steenstra and van den Bergh (2000) and Morton-Williams (1993) found that interviewers who were allowed to adapt their introductory script had greater success. Further, work by Conrad et al. (2013) demonstrated that a moderate use of fillers such as "um" and "uh" by interviewers can lead to greater success, possibly because these interviewers sound like they are engaged in a natural conversation, rather than following a script.

It could behoove survey organizations to conduct research around which elements of speech (increased use of fillers such as "um" and "uh," maintenance of natural intonation patterns, and "on the spot" adaptation of scripts) can be taught and then to focus on training interviewers to use these techniques.

Beyond the introduction, the issue of standardized interviewing, and what departures from verbatim interview scripts can mean for data quality, is the subject of much debate. Schober and Conrad (1997) and Conrad and Schober (2000) found clear evidence that "conversational" interviewing, or less rigid adherence to interview scripts, can enhance data accuracy. Along similar lines, Dykema et al. (1997) found that interviewer deviations from standard question wording had minimal impact on respondents' reports. Still, "reading the questions exactly as worded" is a tenet of interview administration which is upheld and enforced in most survey organizations (Broome 2012).

Because emphasizing the need to read questions in a standardized manner may seem in conflict with emphasis on less scripted delivery of introductions, interviewers need to be trained to "wear two hats." It needs to be made explicit to interviewers that there are two distinct (but, arguably, equally important) elements of the phone component of their job, each requiring a different style of speech and interaction. In the introductory or persuasive portion, scriptedness may be a liability, and the ability to "think on one's feet" to respond to answerers is an asset. In contrast, in the interviewing portion, deviating from a script may have ramifications for data quality or, at the very least, will represent a lack of adherence to the organization's procedures. Interviewers should be trained to "switch gears" between these two speech styles and perhaps even be encouraged to acknowledge to respondents that their delivery of the questions will sound different from their introduction.

4.2 Recommendation #2: Train Interviewer Speech Rates; Consider Implementing Hiring Criteria around Vocal Pitch

It may be a worthwhile investment by research organizations to place greater emphasis on interviewers' vocal characteristics. Speech rate in particular is something that can be trained and monitored. Benkí et al. (2011) found that a rate of 3.5 words per second during the introduction is ideal in obtaining cooperation. This rate is fast enough to sound self-assured, but not so fast as to be incomprehensible. Notably, this is higher than the rate of two words per second, which is often suggested anecdotally as an ideal speech rate for delivering interview questions. Just as interviewers may be able to be trained to speak in a less scripted manner during an introduction and more so during an interview, they can be trained to slow down their speech noticeably after the introduction. This type of training could be implemented with the use of software measuring speech rate and displaying it to the interviewer as she talks (similar to speed clocks which show drivers their current speed); interviewers could slow down or speed up their speech in response, and eventually learn how it feels and sounds to speak at a rate of 3.5 (for an introduction) or 2.0 (for question delivery) words per second.

Additionally, Benkí et al. (2011) found lower pitch over the course of a contact to be associated with success. If further research can substantiate these findings, survey organizations may want to limit their hiring to interviewers who are capable of hitting an optimal pitch range (or avoiding a pitch range which is associated with negative impressions and lower success).

4.3 Recommendation #3: Emphasize Responsiveness to Answerer Concerns

While scriptedness and vocal characteristics in the initial seconds of a survey introduction are important, it is important to note that an interviewer's ability to be responsive to answerers is absolutely critical, whether they are addressing concerns or "taking the bait" by responding to conversation starters. Practicing by interviewers of appropriate responses to common answerer concerns should be a top priority in interviewer training; as Groves and McGonagle (2001) demonstrated, interviewers trained in effective responding have greater success.

4.4 Recommendation #4: Train Interviewers to be Aware of and Respond to both "Red Flags" and "Green Lights" from Answerers

Some answerer comments should be viewed as "red flags," or warnings that the contact is about to end. Particular attention should be paid to concerns in the "I'm not interested" category. Interviewers often treat statements in this category as symptoms of a different concern and, instead of addressing the answerer's stated lack of

interest, attempt to uncover a more addressable concern, such as a lack of time or worries about privacy. Findings by Pondman (1998) show that asking answerers to elaborate on this type of remark (as in, “May I ask why you don’t want to participate?”) can have disastrous consequences, sending the answerer on a tirade of negativity and leading to hang-ups at comparable rates as when this question is not asked. Instead, interviewers may have better success by addressing lack of interest in and of itself as a legitimate concern, rather than treating it as a symptom of another concern. Still, statements of disinterest often indicate an impending hang-up and should be treated as red flags by interviewers.

On the other hand, some answerer utterances can be viewed as “green lights,” or signals that the answerer is open to participating. Questions about the length or content of the survey are more common in contacts where the answerer ultimately agrees to participate. Similarly, the presentations of conversation starters by answerers, such as questions directed at the interviewer or comments peripheral to the task at hand, are not only more frequent than concerns in agree contacts, but are much more frequent in agree compared to refusal contacts and should be viewed as signs of engagement and likely participation.

Other research has looked at utterances by answerers that may indicate a greater likelihood of agreement. Work by Conrad et al. (2013) found that answerers who use more backchannels such as “mm-hmm” or “I see” seem to be indicating engagement in the conversation. These answerers are more likely to agree with the survey request than those who use fewer backchannels.

Being attuned to green lights in answerer speech, such as backchannels, questions about length or content, or the presentation of more conversation starters relative to the expression of concerns, can help interviewers know when an answerer is likely to agree and adapt their introduction in turn. In such a case, backing off from a “hard sell” may be recommended; however, it may also be advisable for interviewers to gently urge the answerer to begin the interview, rather than schedule a callback.

5 Conclusion and Future Directions

Using the findings from studies on interviewer speech in phone survey introductions can help research organizations inform interviewer training and requirements. Specifically, findings show that less scripted speech in the initial seconds of an introduction can help interviewers to keep potential respondents on the phone. Further, interviewer responsiveness to potential respondents’ concerns and conversation starters lead to greater likelihood of participation. Finally, aspects of interviewer speech, such as pitch and rate, may result in higher response rates. Implementing these recommendations can help survey organizations increase efficiencies and potentially reduce nonresponse error.

There is also room for additional research in this area that can add depth to the findings discussed above. Questions for further work may include:

- Does gender, either of interviewer or answerer, interact with the importance of sounding responsive or nonscripted?
- What is the relationship between ratings of scriptedness and actual paralinguistic measures, such as pauses and fillers (“um,” “uh”)? Is there an ideal rate of fillers and pauses in successful invitations?
- When thinking about “red flags” and “green lights” from answerers in the introduction, is there any specific content (e.g., statements of “I’m not interested”) that interviewers can be trained to address?

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The Freelisting Method

82

Marsha B. Quinlan

Contents

1	Introduction	1432
2	To Freelist or Not	1433
3	Using Written, Electronic, or Oral Interviews	1435
4	Focusing the Domain	1436
5	Freelist Analysis	1438
6	Checking Freelists with Ethnographic Interviews	1440
7	Conclusion and Future Directions	1443
	References	1443

Abstract

A freelist is a mental inventory of items an individual thinks of within a given category. Freelists reveal cultural “salience” of particular notions within groups, and variation in individuals’ topical knowledge across groups. The ease and accuracy of freelist interviewing, or freelisting, makes it ideal for collecting data on health knowledge and beliefs from relatively large samples. Successful freelisting requires researchers to break the research topic into honed categories. Research participants presented with broad prompts tend to “unpack” mental subcategories and may omit (forget) common items or categories. Researchers should find subdomains to present individually for participants to unpack in separate smaller freelists. Researchers may focus the freelist prompts through successive freelisting, pile sorts, or focus group-interviews. Written freelisting among literate populations allows for rapid data collection, possibly from multiple individuals simultaneously. Among nonliterate peoples, using oral freelists remains a relatively rapid method; however, interviewers must prevent bystanders from “contaminating” individual interviewees’ lists. Researchers should cross-

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1431

check freelist responses with informal methods as much as practicable to contextualize and understand the references therein. With proper attention to detail, freelisting can amass high quality data on people's medical understanding, attitudes, and behaviors.

Keywords

Freelist · Free recall · Salience analysis · Systematic data collection · Domain analysis · Rapid Ethnographic Assessment (REA) approaches

1 Introduction

Freelisting is a qualitative, easily quantifiable method. Freelists quickly and easily amass data that (1) identifies items in a cultural domain, or emic category; (2) indicates which of those things are most important, or salient within the culture; and (3) reveals how much variation there is in the knowledge or beliefs in question (Quinlan 2016). In a freelist interview, a respondent simply lists members (things) that they perceive to be part of a domain (e.g., “ways to avoid HIV,” “breakfast foods,” “reasons to fear hospitals,” or “treatments for a cough”) in whatever order they come to mind. The resulting lists tap into local knowledge and its variation in a study community. Hence, the method is well suited to find “knowledge, attitudes, and practices” (KAP); ethnomedical beliefs; and some types of prevalence.

Freelisting is a well-established ethnographic method that rests on three assumptions (e.g., Romney and D’Andrade 1964; Henley 1969; Bolton et al. 1980). First, when people freelist, they tend to list terms in order of familiarity. When listing kinship terms, for example, people generally list “mother” before “aunt,” and “aunt” before “great-aunt” (Romney and D’Andrade 1964). Second, individuals who know a lot about a subject list more terms than people who know less. For instance, people who can look at an unlabeled map and correctly name many countries also make long freelists of country names (Brewer 1995). And third, terms that most respondents mention indicate locally prominent items: Pennsylvanians list “apple” and “birch” trees more frequently and earlier than they do “orange” or “palm” trees (Gatewood 1983).

Recognition of freelisting as a productive method for health research is increasing. Bayliss et al. (2003), for example, conducted freelisting to find barriers to self-care among Denver patients with chronic comorbid medical problems. In a series of team health studies, Frances Barg successfully employed freelisting on diverse medical topics including women’s views of urinary incontinence (Bradway and Barg 2006; Bradway et al. 2010); nutrition concepts and strategies among Philadelphia urban poor (Lucan et al. 2012); parental and pediatrician decision-making for ADHD (Fiks et al. 2011); and perspectives of patients, caregivers, and clinicians on heart failure management (Ahmad et al. 2015). Bolton and Tang employed freelists and associated semi-structured interviewing during postdisaster periods, and recommend freelisting in such situations, in which researchers need an ethnographic method that is “both quick and easy to implement” (2004, p. 97). They argue that such interviewing on local names and common manifestations of health problems,

and locally accepted treatments for those problems in affected communities, results in interventions that are more acceptable to local people, thus more effective and sustainable. Finally, freelisting has been used in many studies of medical ethnobotany (e.g., Trotter 1981; Crandon-Malamud 1991; Berlin and Berlin 1996; Nolan and Robbins 1999; Ryan et al. 2000; Nolan 2001, 2004; Finerman and Sackett 2003; Quinlan 2004, 2010; Quinlan and Quinlan 2007; Pieroni et al. 2008; Waldstein 2006; Ceuterick et al. 2008; Giovannini and Heinrich 2009; Mathez-Stiefel et al. 2012; Flores and Quinlan 2014).

In principle, there is a distinction between freelists and open-ended surveying. Freelists inquire about *cultural* domains, while open-ended questions ask for information about the informant (Borgatti 1999). Asking someone to list “medicines *you* use” is an open-ended survey, while asking for “medicines *people here* use” is a true freelist. In practice, it makes sense to consider a freelist a *kind* of survey, and the distinction between freelisting and open-ended surveying may be inconsequential as individuals often answer both open-ended surveys and freelists from a personal perspective. In the over 1,000 oral freelists I conducted on medicines people use in Dominica, it was common, if not typical, for interviewees to respond as though I had asked about a personal attribute, though I asked about a general cultural one. Instead of responding, “People here use...,” they replied in the first person singular or plural (e.g., “I’m using...” or “We’re using...”). If the egocentric perspective is normal in freelists, it would explain why, in freelists of kin terms, Romney and D’Andrade’s (1964) High School informants (who presumably had parents but probably not offspring) listed “mother” and “father” much more than “son” or “daughter,” and while several listed grandparental terms, very few listed grandchildren terms. My experience leads me to conclude that individuals’ freelists are largely personal or egocentric, although this may vary according to culture or topic. The difference between freelisting and open-ended (freelist styled) surveys may be insignificant for many research questions. However, each researcher must decide whether a tendency to respond personally is an important concern. In either case, one could analyze the lists for salience.

Drawing mostly upon my ethnomedical research in rural Dominica, West Indies, in this chapter, I describe the advantages and obstacles of using freelists. Freelist interviews allowed me to (1) find culturally important illnesses, (2) identify local herbal treatments for those illnesses, and (3) explore sociodemographic variables associated with treatment knowledge. Specifically, I discuss five issues for efficient use of freelists in the field: (1) whether to conduct freelist interviews or not, (2) whether to collect oral or written lists, (3) focusing the domain of each freelist interview, (4) types of freelist analysis, and (5) cross-checking freelists with ethnographic interviewing.

2 To Freelist or Not

Freelists provide inventories and boundaries of cultural domains. In health social science, the freelist method is ideal if one wants to find the most culturally salient knowledge (e.g., cut treatment, mosquito control); attitudes towards, or associations with, an issue or topic (e.g., obesity, vaccinations, violence); or different ways locals

do something (e.g., prepare a medicine or a food, decide on healthcare). Freelisted data allows the researcher to discover the relative salience of items across all respondents within a given domain. Salience is a statistic accounting for rank and frequency (e.g., in the domain of English color terms, “red” is more salient – it appears more often and earlier in freelists – than “maroon” [Smith et al. 1995]). Researchers can calculate the mean salience value for all listed items, to reveal the intracultural salience of each term (below). Researchers can also compare individuals’ lists to assess who in a community knows more (or less) about a certain domain of knowledge.

A potential shortcoming of freelisting is that inventories may not be as exhaustive as inventories gained through other methods. For example, medical ethnobotanists normally rely on key informant interviews with local plant experts, including “field interviews,” i.e., walking through vegetation zones or plots with informants and noting every useful plant found (Alexiades 1996, pp. 65–66). Long interviews with key informants may offer informants visual cues and allow or encourage informants to remember more obscure species. Conducting several long interviews may generate more exhaustive inventories than freelists.

The specificity of domains can limit freelists. For example, my freelists on illnesses that Dominicans “cure” with “bush medicine” did not yield the multiple gynecological conditions for which Dominicans use bush (herbal) medicine (Flores and Quinlan 2014). Dominicans regard childbirth, menstruation, and so on as normal events for healthy women, not illnesses requiring a “cure.” Another factor limiting freelists is that they only reflect terms in a respondent’s active vocabulary (or lexical command). Informants are able to recognize more items in a domain than they can freelist from memory (Hutchinson 1983). Researchers can, however, maximize freelist output through supplementary prompting (see Brewer 2002; Gravlee et al. 2012).

The advantages of freelisting outweigh the possibility of reduced inventory, in most cases. First, freelists, unlike less-structured interviews, are rapid and simple. They allow for much larger samples in less time. Other rapid interview methods require the researcher to have prior expertise in the domain. Recognition tasks, questionnaires, sorting, and ranking interviews, for example, have predetermined responses built into the instrument (see Bernard 2011). Second, unlike data from less-structured interviewing, freelists are quantifiable. As Handwerker and Borgatti (2014, p. 520) argue, “even simple forms of numerical reasoning add important components to ethnographic research...Reasoning with numbers reveals things you’d otherwise miss.” Focused freelists gather every significant or salient item that the population associates with a domain, and freelist data allows one to find areas of consensus or high modality within the community (Boster 1987; D’Andrade 1987; Weller 1987). In addition, an informant’s list length is a measure of that person’s depth of knowledge or familiarity within a domain (Gatewood 1983, 1984; Borgatti 1990; Brewer 1995; Furlow 2003). Thus, a researcher can use freelists to identify community experts or examine intracultural variation (Quinlan 2000). One can examine freelists’ content comparatively. For example, rural Missouri novices in wild plant use listed highly recognizable, ecologically salient

species like blackberry and sunflower, while experts listed greater proportions of plain, herbaceous species native to the region, like burdock and plantain (Nolan 2002). In a study of postpartum problems and associated etiologies, signs, and care in Matlab, Bangladesh, Hruschka et al. (2008) found agreement of mentions among local lay women and “traditional birth attendants,” while “skilled birth attendants” (i.e., accredited health professionals) had different (biomedical) responses.

3 Using Written, Electronic, or Oral Interviews

In fully literate communities in which the terms sought (e.g., plant names, illnesses, and so on) are in a written language, researchers can provide freelist interview schedules for informants to fill in themselves. Interview sheets simply contain a prompt written above a series of blanks. If the research participants have computer/smartphone and internet access, web-based freelisting surveys are another written option (see Gravlee et al. 2012). These self-administered methods may work well with developed, industrialized populations. Self-administered freelists offer the advantage of privacy, which is good for getting uncontaminated responses that best test for intracultural variation, and privacy is best for potentially touchy topics.

Freelist interviews can also be oral (face-to-face). For example, I collected oral freelists in Dominica. Rural Dominicans vary in literacy. Most herbal medicine names are in French Patois, a largely unwritten Creole language, in which residents struggle (more than they do in English) to spell (sound-out) words. However, collecting oral freelists did complicate the freelist procedure because making oral lists is less formal and less independent than completing a written list. While informally listing plants, participants sometimes called out for help from nearby friends or family who (trying to help) shared various remedies. Every so often, somebody saw another villager doing an interview, approached out of curiosity, and offered suggestions. These occasions were difficult because the freelists should contain the items that one individual knows in the order that they come to mind *for that individual*.

Research assistants and I dealt with shared-answer events in several ways according to the situation. For example, one woman I interviewed had listed two cures for the common cold when the name of a third slipped her mind. Her aunt was about 30 feet away, and the woman called out, “Auntie! What that bush we using for the cold, na?” “*Timayok!*” the aunt screamed back. The woman had already listed *timayok*. “No, the other one!” The aunt yelled, “Hibiscus flower.” “Yes, but there’s another one again,” the woman said to the aunt. The freelister turned to me and said, “Hibiscus flower is good too, you know. We using that plenty for colds.” “*Pachuri?*” the aunt called. “THAT is it! *Pachuri,*” the woman said to the aunt and me. In this case, I continued with the woman’s freelist, leaving a blank space in the third position, writing “hibiscus” in the fourth position, then, filling “*pachuri*” in the third position, because that was the one the woman was thinking of when she involved the aunt. In some cases, we abandoned the freelists for a later time, as it was less than clear in what order the interviewee would have thought of the herb, had

he or she not been prompted. Leaving an interview because of compromised data was discouraging and consultants were sometimes miffed when I or another interviewer returned to try again.

We learned to avoid most compromised freelist situations by explaining the project to all the nearby adults, and isolating the informant somewhat by stepping around a corner. Had villagers been writing their own responses, rather than listing them aloud, they still may have called out for memory help, or received suggestions from curious bystanders, but probably less often. Written exercises are inherently more private, but they may not be of higher quality. Gravlee et al. (2012) conducted an experiment to compare university students' freelist responses in face-to-face oral interviews, hand-written, and online freelists. They found that all three modes identified the same salient members of each domain. They also found that the face-to-face interviews had the fewest items per respondent but the most agreement. It is possible that the social nature of the face-to-face mode may elicit slightly more thoughtfulness, concentration, or self-editing.

4 Focusing the Domain

Freelists are an advisable method for accumulating inventories. Yet, they *may* not yield a *total* knowledge. Interviewees commonly forget to list items in a domain or (for expediency) intentionally omit items they know (Brewer 2002). Omissions are, in my experience, most likely if the freelist prompt is broad. Freelist data is ranked so that the order in which people list items reveals psychological or cultural preeminence of items *given a certain prompt*. The more focused the prompt, the more complete the freelist will be for that subject whereas vague, general prompts result in broad, scattered lists of questionable utility (Drawing the line on *how much* to focus one's prompt depends on the research question at hand. Cultural experts could potentially parse out items until each prompt corresponds with only a single item.).

Freelists must deal with a single mental category, called a semantic domain (Weller and Romney 1988; Bernard 2017). If the prompted domain is broad, the inventory in the freelist often consists of clusters of subdomains (mental categories). In an experiment (Quinlan 2016), I asked Ball State University students to complete two freelists on birds. In the first, they named "all the birds you can think of." Responses on these lists were diverse, many listing eagles or (American) bald eagles first, followed by other raptors or by pet bird species, or poultry species, or local wild species, but generally clustering by domains as students unpacked their mental clusters of birds. In the second freelist, done some time later, they named "backyard birds in Indiana." Cardinals (the Ball State mascot) were most salient, followed by robins. One informant stated that "robins" were one of the first birds she learned to name as a child. Indeed, in her freelist of backyard birds, robins were highly ranked, third in a list of 16. In her freelist of *all* birds, however, robins appeared near the list's end, emerging as an "afterthought." Before this informant listed "robin," she listed a series of pet birds (one mental domain for her); followed by a series of colorful, exotic birds such as macaws and toucans; then, some raptors; some poultry birds;

and finally, common local wild birds, including robins. In every case, students listed more local birds with the “backyard bird” prompt than in their “all the birds” lists.

In Dominica, open-ended pilot surveys (e.g., Borgatti 1999), in which I asked consultants to list “all the *bush medicines* [herbal remedies] people use,” were similarly too broad. Lists contained clusters of subdomains, usually grouped into treatments for particular ailments, though sometimes grouped by the individuals that grew/used the plant, plant size/shape, and so on. Further, many species – later identified as leading treatments for common illnesses – were missing from these broad lists, presumably because the treatment’s subdomain (a particular illness) did not occur to the informant during the interview. Similarly, Saraguro (Ecuadorian Andean) freelisters did not recall several plants in their own home-gardens, omitting scarcer ones (usual in freelists) and also plants that were possibly “too ubiquitous to consider ‘interesting’” (Finerman and Sackett 2003, p. 462).

To make freelists most efficient and accurate, it is helpful (for researchers and consultants alike) to narrow the freelist’s domain. It is easier, for example, for someone to list “all of the over-the-counter medicines in your house” than “all of the over-the-counter medicines at your pharmacy,” and easier still to list “all of the over-the-counter medicines in your medicine cabinet.” Asking someone to list *sore throat* medicines that he knows is less daunting and less bother than listing *every* medicine he knows of. Researchers should identify relevant, focused domains, and then conduct freelists on the content of each domain. The researcher thus runs several short, noninvasive interviews, which, when combined, may be more complete than one broad interview.

In cases in which essential categories are not apparent, one might focus domains using either successive freelisting or ethnographic interviews (see below). Successive freelisting is an accurate, efficient method of honing domains. Here, a researcher uses the responses from one freelist as topics for subsequent freelist interviews, yielding related lists of subdomains. Ryan et al. (2000) offer a detailed description of collection and analysis using this technique. I provide one ethnobotanical example.

After conducting the aforementioned unsatisfactory pilot interviews on all *bush medicines*, I conducted a series of freelists focusing on illnesses Dominicans know how to treat with medicinal plants. I used a prompt in the local English Creole (developed with key informants to aid comprehension): “Here in Bwa Mawego [the village], what things they curing with bush medicine?” I collected freelists from a quota sample of 30 adult villagers stratified by age, sex, and village location (see Quinlan 2004), or approximately one fourth of resident adults. These freelists were oral and I wrote informant’s responses as they listed the illnesses. Each freelist of illnesses took between 2 and 10 min.

I compiled this data (using the calculations outlined below) and ascertained the most salient treatable illnesses. Twenty-one illnesses terms were highly salient, but focus groups found and consolidated redundant and related salient terms. The final list contained 18 prominent illness domains.

This project’s ultimate objective was to find rural Dominicans’ customary (or prevalent) medicinal plants. Research assistants and I asked every available adult in the village to freelist bush remedies for each of the 18 illness-domains.

For most people, each freelist of a domain took much less than 1 min. We could usually do all 18 freelists in one sitting with each villager. When we surveyed the whole village with the 18 short freelists, we reinterviewed the individuals who participated in the long *pilot* interviews (in which they named “all” bush medicines). When I summed the separate medicinal species that the former consultants mentioned in the domain-focused exercise, they all had mentioned more species in multiple short freelists than they had in their initial long open-ended survey. Few informants became bored, frustrated, or overwhelmed during the domain-focused freelists because each of the 18 tasks was simple, quick, and different. Numerous people enjoyed their freelisting tasks and returned to the interviewers with their kin and friends who wanted a turn at it. Together, we obtained 1,826 freelists from 126 adults (almost all present in the village), yielding 7,235 total responses (see Quinlan 2004, 2010; Quinlan and Quinlan 2007; Quinlan et al. 2016; Quinlan and Flores *in press*).

5 Freelist Analysis

Freelist data reveals information about the items people list and the people who list them. The data inherently demonstrates a kind of cultural agreement (Weller and Romney 1988; Furlow 2003). Frequently mentioned items (or species) among individuals indicate common knowledge, or consensus, within the culture. And, the differences in list length and content are measures of intracultural variation.

Salience analysis (or Smith’s S) (see Smith 1993) accounts for frequency of mention; however, it is weighted for list position as well. Thus, with my freelists of illnesses people treated with bush medicine, the calculation showed salience estimates for each illness, indicating both the number of people who mentioned the illness, and the order of their responses.

The salience statistic is simple enough to calculate quickly by hand. There are two steps. First, one needs to find salience of listed items (S) for each individual. Here, one ranks items on an individual’s list inversely (final item listed equals one and items increase by one moving up the list). Then one divides the rank by the number of items the individual listed (see Table 1). Second, one tabulates a *composite* salience value (CSV) (or mean salience value) for each item listed in all freelists of the domain. Here, one sums all salience scores for that item then divides by the number of informants (see Table 2). ANTHROPAC 4.98 Windows freelist program software (Borgatti 1992) simplifies the entry and salience analysis of freelist data, which is useful with large samples, but which one can also compute in a spreadsheet program, as shown in Tables 1 and 2.

Determining which items are salient is not standardized. Drawing this boundary is a matter of judgment because salience is relative (Quinlan 2016, p. 8). In my experience, there are often visible breaks in the data that make good margins. The first break in salience occurs between items that many people think of and those that only some recall. In Fig. 1 of freelists of Dominican treatments for boils (Quinlan 2000), many people listed *malestomak*, *planté*, and “soft candle” (dripped tallow

Table 1 Weighting salience of items (illnesses) for freelister 1

Illness	Inverted rank	Divide by total listed	Salience (S)
Worms	5	$\div 5$	1
Cold	4	$\div 5$	0.8
Vomiting	3	$\div 5$	0.6
Sore throat	2	$\div 5$	0.4
Sprain	1	$\div 5$	0.2

Note: For the sake of illustration, this freelist and all lists in Tables 1, 2, and 3 are abbreviated

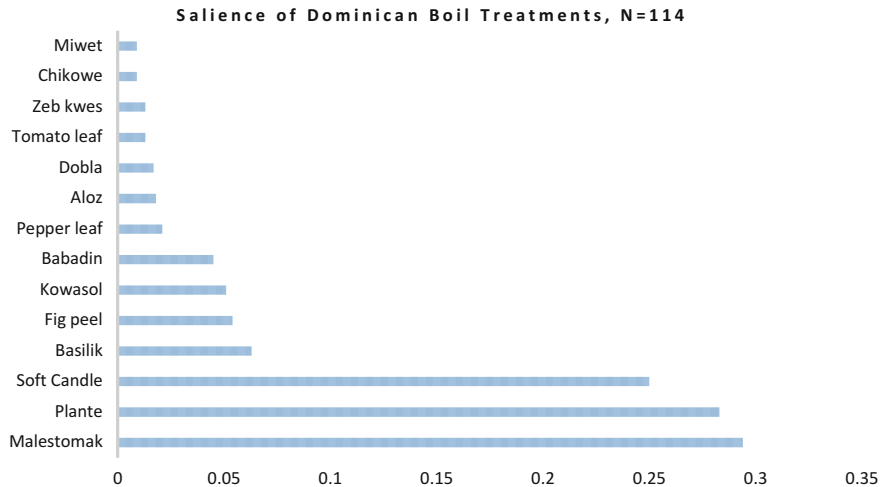
Table 2 Determining composite salience for three freelisters

Illness	Freelist 1	Freelist 2	Freelist 3	Illness Σ	Composite salience Σ/n ($n = 3$)
Worms	1	0.875	1	2.875	0.958
Cold	0.8	1	0.5	2.3	0.767
Buttons		0.75	0.75	1.5	0.500
Vomiting	0.6	0.625		1.225	0.408
Pressure		0.5	0.625	1.125	0.375
Inflammation			0.875	0.875	0.292
Cough		0.375	0.35	0.725	0.242
Sore throat	0.4		0.25	0.65	0.217
Asthma		0.25		0.25	0.083
Sprains	0.2			0.2	0.067
Cuts			0.125	0.125	0.042
Shock		0.125		0.125	0.042

Note: Column 2 contains S of freelist 1 (From Table 1). Responses of two other individuals (freelisters 2 and 3) are in columns 3 and 4. For every item (illness), sum individuals' salience scores (Illness Σ) then divide by the sample size (number of freelisters)

candle wax): These were highly salient. Some people listed the subsequent four treatments (*basilik* through *babadin*) – which are somewhat salient and worth inclusion under most circumstances, depending on the researchers objectives. Pepper leaf, *aloz*, and tomato leaf are not very salient, but because they were listed by three or four individuals, they likely are indeed local boil treatments, and though less salient might be retained in inclusive considerations. The straggling items (*zeb kwes* through *miwet*) are either uncommon or a “mistake,” as with the informant who freelisted “turnip” as a fruit for Weller and Romney (1988). *Dobla*, though listed by only two individuals like the three least salient items, has higher salience, meaning that it ranked relatively highly among the individuals who listed it. I would not consider it “salient,” but worthy of further investigation. Bernard (2011, p. 349) offers as a rule of thumb that items mentioned by 10% of informants be considered salient.

Robbins et al. (2017) improve on Robbins and Nolan (1997) and Ryan et al. (2000) by adding a technique to examine clustering of freelist data, such that one might use freelists to examine cognitive arrangement of emic or etic categories within a domain, across and within freelists of varied lengths. An ethnobotanist might, for example,



	Malestomak	Plante	Soft Candle	Basilik	Fig peel	Kowasol	Babadin	Pepper leaf	Aloz	Dobra	Tomato leaf	Zeb kwes	Chikowe	Miwet
Salience	0.294	0.283	0.25	0.063	0.054	0.051	0.045	0.021	0.02	0.017	0.013	0.013	0.009	0.009
Frequency	30	37	29	9	8	8	8	4	4	2	3	2	2	2

Note: For species names of treatments (mostly given in French Patois), see Quinlan and Flores (in press), or Quinlan (2000).

Fig. 1 Dominican treatments for boils. Note: For species names of treatments (mostly given in French Patois), see Quinlan and Flores (in press), or Quinlan (2000)

examine the psychological/cultural salience of plants with perceived humoral qualities, or weeds versus cultivates, or flowering versus nonflowering plants.

In addition to revealing culturally salient items across individuals, freelists measure individuals' expertise within a domain. As mentioned above, knowledgeable people tend to have longer lists. By creating an individual by item matrix one can tabulate items' frequency of mention (Table 3, row totals), and individuals list lengths (Table 3, column totals). With additional sociodemographic data, one can investigate relationships between people's knowledge in a domain and other characteristics such as residence or education-level. I found, for example, that Dominicans' mean list-length of bush medicines positively correlates with age and wealth (Quinlan 2000).

6 Checking Freelists with Ethnographic Interviews

The value of the freelisting technique depends on understanding the cultural domains in question. Informal interviews (such as key informants, focus groups, and so on) in conjunction with freelists permit "ethnographic cross-checking," which

Table 3 Comparing individuals' knowledge

Illness	Freelister 1	Freelister 2	Freelister 3	Illness frequency
Worms	1	1	1	3
Cold	1	1	1	3
Buttons	0	1	1	2
Vomiting	1	1	0	2
Pressure	0	1	1	2
Inflammation	0	0	1	1
Cough	0	1	1	2
Sore throat	1	0	1	2
Asthma	0	1	0	1
Sprains	1	0	0	1
Cuts	0	0	1	1
Shock	0	1	0	1
Total illnesses listed	5	8	8	21

Note: Salience data from Table 2 converted to ones and zeros for the presence or absence on three informants' freelists (1/0 indicate probable presence/absence of knowledge of bush medicine for that illness)

increases accuracy and enhances the depth of ethnographic understanding. Informal ethnography and freelisting can be complementary sources of information (see also Ethnographic method).

The ideal way to find emic domains is to use successive freelisting cross-checked with ethnographic interviews. I recommend getting freelists from a larger sample, then using the salient subdomains of the original as focus group topics. In focus group interviews (Bernard 2017), several local consultants hash out the different *categories* of X (e.g., cold medicines, stomach medicines, and so on) that have been freelisted. Observing focus groups lets an ethnographer witness locals' decision-making rationales and processes (Trotter et al. 2014) (One could omit successive freelists and use only focus groups here. However, freelisted domains are representative of the population, not swayed by charisma or assertiveness of an individual in a focus group.). Initial time spent going through both freelisting and informal interviewing is worthwhile because it expedites the final set of interviews.

Researchers can use ethnographic interviews to accurately "standardize" freelists. Weller and Romney (1988) warn in *Systematic Data Collection* that when freelists consist of phrases or statements, various lists may contain different phrasings of the same concept. A researcher must then use judgment to standardize concepts before tabulating the lists. In unclear cases, it is "desirable" for informants to identify different phrases that represent a single concept (1988, p. 15). Similarly, freelists of terms often contain synonyms and redundant phrasing (e.g., breastfeeding, breastfeeding, nursing, and lactating) for the researcher to cull out. Different terms in a freelist may not be separate entities. Further, one emic term may refer to more than one etic entity.

My first succession of freelists of illnesses yielded 21 highly salient illness domains. Focus groups responded to the terms indicating that several of them were redundant. In their estimation, “cuts” and “sores,” though different, belonged “together,” as did “prickle-heat” and “buttons” (rashes, pox, and pimples), and “upset stomach” and “vomiting.” After much debate, they agreed that a less salient term “arthritis” did not belong with “rheumatism” (“arthritis” is associated with a culture-specific fright-illness in Dominica, while “rheumatism” is not). Here, using focus groups streamlined my interviewing process and lent “emic authority” to the final domains. Without input from the focus groups, I would have performed several superfluous interviews with each subject. Or, if I had deleted redundancies on my own, I would have, despite extensive experience with the local medical system, grouped domains differently.

Final freelists in a succession also contain synonyms and require standardization. Lay people generally use local common names for illnesses, plants, body parts, and so forth. Does “stomach” refer to the single organ or to the general area? Is it synonymous with gut and belly? Plant foods and medicines’ common names are often not exact (thus the necessity of Latin species names). Plants often have multiple, distinct-sounding common names that people in a population use interchangeably (e.g., “scallion” and “green onion”), which can be confusing for an outsider.

The problem of several terms for one species multiplies in societies influenced by multiple languages. Anecdotally, with greater Hispanic influence in the USA, *Coriandrum sativum* L. has become a relatively common cooking ingredient, and the Spanish common name “cilantro” appears at least as prevalently as the herb’s English common names, “coriander” and “Chinese parsley.” One species that may have numerous monikers wherever it is used is *Cannabis sativa* L. In Dominica, it is *kali* in both French Patois and English, *zeb* in Patois, and “marihuana,” “weed,” “sensi,” and “ganja” in English. In addition to single species with multiple names, people identify separate, related species by one generic name (Berlin 1992), such as “begonia” for various species in the genus *Begonia*. This confusion is not unique to plants, one might wonder whether football means American football or soccer. Thus, conducting interviews in which local consultants identify plants or discuss topics in the lists, in addition to freelisting, is the only way to ensure accuracy of inventories from freelists.

Once terms are standardized and analysis reveals salient terms, ethnographic interviews can fill information about salient items. In medical ethnobotany, for example, informants can describe combinations, preparations, and doses of the salient medicinals, and the circumstances in which each plant might be preferred. For example, among salient Dominican treatments for “worms,” *sime kontwa* (*Chenopodium ambrosioides* L.) is a general-purpose vermifuge, while *twef* (*Aristolochia trilobata* L.) is for severe cases, and *kupiyè* (*Portulaca oleracea* L.) is best for children (Quinlan et al., 2002). In another example, “soft candle” wax, the third most salient boil treatment (Fig. 1), is used to plaster a medicinal leaf over a boil, but is not a treatment alone (Quinlan 2000).

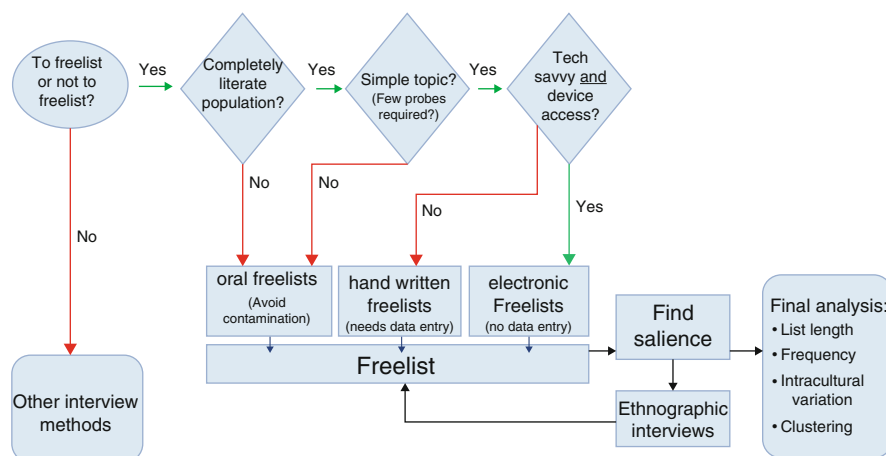


Fig. 2 The ideal freelisting process (modified from Quinlan 2016)

7 Conclusion and Future Directions

Freelisting is a simple, accurate, and quick way to collect data from a large sample of individuals. Freelists reveal the salience of items in the community and variation in knowledge of the domain in question. Among literate communities, written freelists provide privacy and avoid data contamination from spectators, but may be less considered than face-to-face interviews. Interviewers conducting oral freelists should take steps to prevent bystander “contamination.” Freelists are especially useful in an iterative or successive process, as outlined in Fig. 2. Generally, researchers should hone domains of freelists tightly: Given broad topical areas, people tend to forget or omit items. They also cluster their responses as they “unpack” their mental subcategories. Omission and clustering of terms may reduce precision of salience estimates.

Using successive freelists factors out mental subdomains from the original topic. Final interviews in the iterative process are fast (and often enjoyable) for informants, and are most complete and accurate for investigators. Researchers should check responses from freelists with informal methods. Determining emic definitions of the terms in a domain is necessary to prevent over- or undercounting responses. Informal methods can also reveal other information about salient items (e.g., how, when, or where the item is appropriate or occurs). With proper attention to detail, freelisting can result in large amounts of high quality sociocultural health data.

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Solicited Diary Methods

83

Christine Milligan and Ruth Bartlett

Contents

1	Introduction	1448
2	The Solicited Diary: Methodological Underpinnings	1449
3	Approaches to Solicited Diary Method	1451
3.1	What Sorts of Questions Can Solicited Diaries Address?	1452
3.2	Semi and Unstructured Approaches to Solicited Diary Method	1452
4	Solicited Diary Techniques and “Capture” Technologies	1454
5	Analyzing Diary Data	1456
5.1	Analyzing Written Diary Data	1456
5.2	Analyzing Visual Diary Data	1457
6	Strengths and Limitations of Solicited Diary Method	1457
7	Addressing the Limitations of Diary Methods	1459
8	Diary Methods: Practical Examples	1460
9	Conclusion and Future Directions	1461
	References	1462

Abstract

To date, solicited diaries have been relatively neglected as a research method within the health and social sciences. Yet, the gathering of chronologically organized diary data can provide unique insights into the life-worlds inhabited by individuals; their experiences, actions, behaviors, and emotions and how these are played out across time and space. Solicited diaries enable informants to actively participate in both recording and reflecting (either in written, oral, or

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visual formats) on their own data. While inevitably these data are reflected upon with a certain research agenda in mind, most qualitative diary methods allow space and time for diarists to depict their own priorities. As such, this research technique affords participants greater control of the data, enabling individuals to not only consider their responses but reveal as little or as much as they feel willing to do so. Solicited diary methods can be used to gather both qualitative and quantitative data, but in this chapter we focus specifically on the use of qualitative diary techniques. We address the methodological underpinnings of these approaches and the contribution they can make to the study of different questions, phenomena, and social problems. We also consider the strengths and limitations of solicited diary methods including debate about the extent to which they are viable techniques for undertaking research with all groups and individuals. Finally, we discuss how the rise of digital technologies is opening up new and exciting approaches for solicited diary techniques, the possibilities for which are only newly being explored.

Keywords

Solicited diaries · Qualitative · Unstructured · Technology · Analysis

1 Introduction

The use of (largely) quantitative solicited diary methods has a history in health research stretching back more than 90 years (Waldron and Evers 1975). In comparison, the use of qualitative solicited diaries has been far less common – particularly in relation to face-to-face methods such as interviewing and focus groups. But, the design and application of solicited diaries has grown significantly over the last 15 years. Indeed, a recent structured search of key databases identified over 64,000 papers published between 2000 and 2014, using solicited diary methods as part of their research design (Rokkan et al. 2015, p. 203). Of course, this does not differentiate between structured and semi/unstructured diary methods, but it does demonstrate a growing recognition that this technique has the potential to add something different to the repertoire of qualitative methods. Solicited diary method is increasingly being used within research either as the sole method of data collection, or as part of a wider multimethod research design.

So what is a diary, what do we mean by a solicited diary, and how does it differ from the unsolicited diary? Methodologically, the solicited diary is a research technique in which informants actively participate in both recording and reflecting on their own thoughts, feelings, actions, and behaviors. Though written with a specific research agenda in mind, the semi- and unstructured diary also usually enables the diarist to identify his or her own priorities. Rokkan et al. (2015, p. 203) define the diary as “a record of what an individual considers relevant and important in his or her life, for instance; events, activities, interactions, impressions or feelings. It is usually structured by time in some way.” A key distinction between the unsolicited and the solicited diary is that the former consists of a diary that the

individual chooses to keep voluntarily. He or she has not been asked to keep the diary and there is no specific research or other agenda to its completion – even though some can go on to provide the foundation for important historical research. The record of events and experiences in the internationally recognized diaries of Anne Frank or Samuel Pepys are often cited as key examples of this (Bartlett and Milligan 2015). Solicited diaries, on the other hand, are those that people have been asked to keep for a specific reason – in this case, research. Here, the participant is requested to keep a regular record of his/her thoughts, feelings, experiences, and/or behaviors around a specific topic over a defined period of time.

While we acknowledge the long history of structured diary method in health and social research, in this chapter we focus specifically on the use of in-depth semi and unstructured solicited diary methods. These approaches are designed to encourage the diarist to record a more detailed temporal narrative, often around a loosely structured set of themes constructed by the researcher. The aim is to gain a deeper understanding of a person's actions, experiences, thoughts, and feelings around a specific topic over time. These approaches also allow space for the diarist to record his/her own priorities, so can prove useful for capturing the meaning and weight diarists attach to different events and experiences in their lives (Milligan et al. 2005).

We also consider the methodological underpinnings of solicited diary method in the chapter and the implications for ethics and empowerment. The chapter continues with a discussion of the different approaches to solicited diary design and how it can be used in conjunction with other methods to give unique insights into individuals' personal experiences of specific health and social events. We draw on illustrations from our own and other recent research to demonstrate why researchers have chosen to draw on solicited diary methods as part of their research design and how the method has been applied in the field. We are particularly concerned with the novel insights that can be gained from using this approach.

While our chapter focuses on the potential benefits solicited diary techniques can contribute to a researcher's toolbox, like any research method, it has limitations. Our final section discusses these strengths and limitations in order that researchers are alert to what this might mean for their studies and can plan for it, if incorporating solicited diaries into their research design. We conclude with a brief discussion of the newest developments in applying diary method and future directions.

2 The Solicited Diary: Methodological Underpinnings

There are several methodological underpinnings to diary methods, most of which relate to the immediacy and flexibility of this approach. Firstly, diary methods are favored by researchers for gathering data as, and when, it occurs rather than relying on someone recounting an event or feeling after it has happened (as, for example, with a qualitative interview). Diary methods allow the participant to record an experience in real time (or at least closer to the moment that it occurs). The immediacy of diary method – being able to gain a person's perspective on an

event as near to when that event occurs – is important because it can improve the quality of data and open up other ways of knowing about a person's inner world. Indeed, solicited diary methods are often chosen because they have the potential to reduce the recall bias or retrospective censorship that can occur in question-response methods such as interviews (Bartlett and Milligan 2015).

A second methodological reason for using diary methods is because they allow for an extended period of data collection that is relatively unobtrusive. Participants are typically asked to maintain a diary over a certain number of days, weeks, months, or potentially even longer, depending on the phenomenon under investigation and the resources available to the researcher. For example, in the Hull Floods project, as well as undertaking initial in-depth interviews, a panel of 55 people were recruited to keep diaries over a 12–18-month period (Whittle et al. 2010). This allowed for the long-term effects of flooding to be captured in a systematic and impactful way. Hence, diary techniques can “fill in the gaps,” offering insights into what happens between longer intervals in longitudinal approaches (Bijker et al. 2015). Being able to capture changes in circumstances and within-person variations over an extended period of time is vital for many topics in the health and social sciences – coping with substance misuse cravings (Cleveland and Harris 2010) and breastfeeding difficulties for first time mothers (Williamson et al. 2012) to name just two. This can be a key reason for adopting diary method techniques.

A third methodological reason for choosing to use diary method is because it facilitates the reporting of sensitive or otherwise “unseen” behaviors. Several researchers have reported on the value of using diary method to research “taboo” or controversial topics such as sexual activity, obesity, and substance misuse (e.g., Allen 2009; Boone et al. 2013). Sleep is another topic that has been researched using diary method, particularly audio diaries, because the method lends itself to eliciting what sleep researchers have called “narratives of the night” (Hislop et al. 2005). Diary methods are accessible tools, then, that can give researchers rich insights into all aspects of human life.

A fourth methodological reason for using diary methods, specifically video-diary method, is because this method generates rich data about how a person looks, sounds, and moves. As one advocate of video-diary method notes, it can make the body “knowable” (Bates 2013). Information about how a participant speaks, behaves, and experiences ill-health can all be gained through video-diary method – and to some extent through audio and photo diary techniques as well. In our view, one of the best examples of using video-diary method for this methodological reason was a study conducted in the United States investigating younger peoples' experience of asthma (Rich et al. 2000). Here, 25 young people were invited to create a video diary of their day-to-day life with asthma. The researchers were able to capture data about the embodied experience of living with asthma that would not have been possible to gather using any other method. For instance, one 18-year-old participant “videotaped herself in rapidly worsening respiratory distress” as she was being driven to hospital by her mother (p. 67). In such circumstances conducting an interview would be neither possible nor ethical. So insights into this kind of bodily experience can only be gained through immediate, accessible, and visual methods

such as video-diary method, where the decision to record particular diary data lies firmly with the participant (see also ► Chap. 74, “Digital Storytelling Method”).

Finally, it is important to note that, solicited diary methods fit well with a participatory research design, where concerns about participants in the research process are paramount (see Higginbotham and Liamputtong 2015; see also ► Chaps. 17, “Community-Based Participatory Action Research,” and ► 17, “Community-Based Participatory Action Research”). Here, researchers might choose to use a diary method because it allows participant’s to control the pace and time of data collection in ways that other qualitative methods do not. For example, in the asthma study described above, participants were encouraged to “interview” members of their family about their illness experience on camera, thus giving the young people considerable control of the data production process (p. 55). All of the above highlight reasons why a researcher might choose to use a diary method to investigate a topic.

3 Approaches to Solicited Diary Method

The emergence of participatory research designs has led to a greater emphasizes on the importance of “researching with” rather than “researching on” participants (Higginbotham and Liamputtong 2015). This has resulted in a greater consciousness among many qualitative health and social researchers of the need to find ways of reducing the uneven power relationship that often occurs between the researcher and the researched. These are key issues, but it is also important to consider those other qualities of solicited diary method that are important in deciding whether it should be the method of choice in designing a qualitative study.

As previously indicated, a key feature of solicited diary methods are their focus on how an issue of interest occurs or changes over time. A well-designed diary can yield significant insights into the temporality of an individual’s actions or experiences that may not be so accurately gained using other research techniques. The requirement for regular diary contributions made over a defined period of time means that the quality and quantity of data provided is significantly different to that of other research techniques. Indeed, using diary-interview method in a study of scientists’ experiences of working in Antarctica, Filep et al. (2015) observed that the diary process appeared to give participants “permission” to be more expressive and creative in giving data in comparison to their interview data, which was less reflective, briefer, and to the point. Bernays et al. (2014), also using diary-interview method in their study of peoples’ perceptions of hope after being diagnosed with HIV/AIDS, found an added richness in audio diary data. They noted that because participants made their recordings alone, rather than in the company of a researcher, a very “specific communication space” was created that made it possible to “access resistant narratives that are normatively unsayable” – such as feeling suicidal and hopeless (p. 636). In effect, then, diary methods allow a participant to produce a freer, unencumbered narrative. Hence, they have the potential to offer a more comprehensive picture of an individual’s activities, thoughts, and experiences over time.

3.1 What Sorts of Questions Can Solicited Diaries Address?

Before adopting a solicited diary research design, it is important to consider what sort of questions this technique can usefully help to answer – whether as a single method study or as part of a multimethod research design. Following Bolger et al. (2003) we outline a threefold typology of research questions that solicited diary methods can usefully address.

(i) **To gain reliable individual information over time**

Solicited diaries can be useful where accuracy about an individual's experiences, practices, habits, actions, and so on over time are important. They are not only less subject to the vagaries of memory, retrospective censorship, or participants' reframing of data than other methods, they can also be useful where a researcher is interested in uncovering routine, everyday processes and events that may be viewed by the participant as trivial and hence easily forgotten (Milligan et al. 2005; Gill and Liamputtong 2009).

(ii) **To obtain an understanding of within-person change over time and individual differences in such change**

Time may play an important role in understanding embodied responses to internal factors (physical, cognitive, or emotional) or external (social/environmental) factors. Solicited diaries can thus help where research focuses on gathering accurate understandings of how a purposively defined range of an individual's thoughts, feelings, experiences, embodied actions and reactions, etc., to phenomena of interest may (or may not) change over time. These data can then be used to analyze within-person differences in those experiences over time.

(iii) **To conduct causal analysis of between-person changes and individual differences in these changes**

Solicited diaries can help identify underlying causes of change within an individual over time in relation to a phenomena of interest and how these may vary between people. The emphasis of the research here, then, is to uncover those processes that underlie not just within-person variability over time, but *between*-person variability.

3.2 Semi and Unstructured Approaches to Solicited Diary Method

Having confirmed that solicited diaries can usefully contribute to answering the overall aims and objectives of a qualitative study, it is important to consider the form of the diary required. By this we mean, whether a semi or unstructured diary is required and whether written, audio, or visual approaches (or a combination) might be most appropriate. For example, is the study seeking to identify how many times specific events, phenomena, or activities and their variables occur over a prescribed length of time? Is it more concerned with an individual's thoughts, feelings, or the unspoken and often personal actions or experiences that may not be deemed

important by the respondent when engaging with more reactive research techniques? Is the solicited diary being used as the sole method within a study or as part of a multimethod research design? Might technology have a useful role to play in the application of the diary and data collection? These sorts of questions are important in any decision about how solicited diaries should be constructed and what instructions should be given to participants.

Whichever format is undertaken, solicited diaries involve participants being given a clear set of guidelines on how to complete the diary and the frequency with which this should be undertaken. In semistructured diaries, participants are given a set of headings or themes linked to the research objectives and asked to record their experiences of a phenomenon, their activities, thoughts, feelings, and so on in relation to those themes at regular intervals over an agreed period of time. In most cases, participants are also given an opportunity to record other issues that may not be part of the predefined themes, but which *they* feel are important in relation to the study. In unstructured approaches, participants are asked only to record their thoughts/experiences/actions around a phenomenon of interest without being given any thematic prompts. Participants then identify their own priorities around the topic in their diary entries without influence from the researcher.

As noted, solicited diaries can either be used as the sole method of data collection, or as part of a multimethod research design. They can be used as a precursor, an adjunct, or a follow-up to survey, interview, observational, or other research techniques. One commonly adopted multimethod approach is that of the diary-interview method or diary-photograph, diary-interview method (DPDIM) pioneered by Zimmerman and Wieder in the 1970s. Here, the diarist acts as a proxy observer, whose regular diary observations of phenomena are followed up by an in-depth interview with the researcher. Gibson (2002), for example, used audio diaries combined with photographic data and interviews to gain a deeper understanding of experiences of transitioning to adulthood among young men with a disability. The researcher was keen to understand the intersectionality of gender, disability, and life-stage identities. Diarists were encouraged to take photographs that reflected their daily lives alongside their regular diary entries. Orban et al. (2012), in a study of how changes in patterns of daily occupations change over time, used the diary data to construct graphs illustrating the sequences of occupations performed by participants. In both these, and similar studies, the diary was used as a source of information and aide-memoire that facilitated subsequent stimulated-recall interviews using the photographs/graphs to help guide discussion. Gibson (2002) also noted that the ease of operating audio-recorders makes the audio-diary particularly suitable for those with physical functional limitations, as well as enabling the capturing of those subtleties of tone that are not possible in written accounts.

Latham (2003) contends that the integration of the nondiscursive (photographs) within DPIM methods facilitates an exploration of tacit knowledge that is often difficult for individuals to write down or verbalize. He suggests that as a research technique, diary methods are both a reportage of events over time and a performance. The subsequent interview then becomes a reperformance or reaccounting of recorded events and phenomena. He thus argues that rather than seeing the different

ways in which diarists complete their individual diaries as problematic, we should focus on how diary methods enable us to plug into, and enable, participants' existing narrative resources (Latham 2003, p. 2002).

Finally, Gibson (2002) point out that the subsequent interview in diary interview method is not solely a reperformance or reaccounting of the diary data. Rather, "it provides a situation of co-analysis where the interviewer learns from the participant how the image was created, the motivation for including it and what it represents for them" (p. 387).

4 Solicited Diary Techniques and "Capture" Technologies

In the last decade, the application of technologies in diary-based studies has expanded enormously. While a significant rise in published diary studies involving technologies has occurred since 2000, the majority of these have been published within the last decade. Many of these studies involve the use of "capture" technologies such as cameras, voice recorders, and mobile (smart) phones and are exploratory – qualitative – in design. These approaches to diary studies form the focus of this section.

One of the most well-established applications of capture technology in diary-based research is the video-diary method. This involves participants keeping a diary of an activity or experience using a video camera for an agreed period of time. Researchers have used video diaries to explore such themes as the bodily experiences of running (Bates 2013); children's experiences of various life events (Buchwald 2009), such as running away from home (Edinburgh et al. 2013) and learning in school (Noyes 2004). Video-diary methods privilege action and the visible, and are therefore "ideal device[s], with which to unlock bodily experience and bring the sensuous and affective qualities of embodiment to the screen" (Bates 2013, p. 31). Video diaries are unique and innovative modes of data collection. They are fundamentally different from paper-based diaries, in that they generate moving data and allow for the visualization of phenomena. Video-capture technology is thus contributing to the diversification of diary-based research (see ► Chap. 74, "Digital Storytelling Method").

Video-capture technologies are changing diary methods in a number of ways. First, the data generated by video-diary method gives researchers access to areas and situations that might otherwise be prohibited, or go unseen or unknown. Recall the video-diary study mentioned above of young people living with asthma. One diary entry comprised a short video clip of a cat-allergic patient with a kitten hidden in her bed. Another revealed a dusty construction site outside the participant's home. In both cases, the video data furnished the researcher with an intimate knowledge of a child's private space (bedroom), and in particular, the environmental triggers for their asthma. For the young participant, it meant that they did not have to rely on the spoken word to convey their day-to-day lives as the video footage did that for them. Indeed, it transpired in the subsequent interviews, that the young participants were not even aware that cat hair and dust were triggers. Solicited diaries using capture

technologies can thus provide valuable information that the participant may not view as important or may not think to write or verbalize.

Video-capture technologies can also enhance research relations by affording participants greater control over the data production process, than traditional methods allow. Giving the participant the camera means that they make the decisions about the pace and frequency of data collection rather than the researcher. For example, in one video-diary study involving over 70 young girls, the researchers suggested 10 min a day, but most girls chose to film less frequently but for longer (Jackson and Vares 2014). As diary researchers note, participants will keep their diaries in their own way, with the power of selection being handed over to the participant (Bijoux and Myers 2006). This is especially true of video-diary studies, where having a video camera can engender feelings of self-empowerment and control. The evidence suggests this also works well with those people who are not typically seen as being able to take control, such as young children and people with dementia (Capstick 2011).

Another common application of capture technology in diary-based research is the photo diary. This involves participants taking photographs, which capture their experiences and activities, and talking to the researcher about them afterward – a technique known as photo-elicitation (Prosser and Schwartz 1998). The approach originated in anthropology and ethnography and is popular with visual researchers. The following two studies are examples of how photo diaries have been used to investigate areas of academic interest in the health and social sciences:

- Twenty-two secondary school children in New Zealand were issued with disposable cameras to explore sexualities and school culture (Allen 2009).
- Twenty-two parents of preschool aged children were asked to keep a photographic diary to record their child's dietary intake.

Some diary studies use the term photovoice to describe the process of giving participants a camera to record their thoughts and feelings (see, for example, Williams et al. 2016). Photovoice is a similar photographic technique to photo-elicitation, but its roots are firmly in participatory action research (Wang 1999). One practical consideration with any photo-diary method is whether to provide participants with a camera, or ask them to use their own. If you decide to provide participants with a camera, you need to consider whether to provide an analogue (disposable) one, or a digital one. The latter is probably the better of the two options as society becomes increasingly digitalized and allows for ease of transfer of the digital photographs for printing and for analysis. However, both options rely on the researcher having access to sufficient numbers of cameras to disperse to all participants, and therefore can have cost implications. Moreover, each has methodological implications, which may or may not influence your decision. For example, an analogue camera can be easier for some people to operate; plus, the restriction on the amount of images that can be taken, may mean that participants give more thought and consideration to what to photograph (Bartlett and Milligan 2015; see also ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method” and ► 77, “Blogs in Social Research”).

5 Analyzing Diary Data

Techniques for analyzing solicited diary data depend on the research objectives, the medium used to gather the data, and the size of the research team. Where a project involves multiple researchers and data gathered using different media (for example, written, audio, and/or visual data), analysis can be complex and require skill and effort to ensure materials can be practically shared and effectively analyzed (Pink 2009). However, for a sole researcher analyzing written diary data, the process is relatively straightforward.

5.1 Analyzing Written Diary Data

Quantitative methods of analysis can be applied to semi- and unstructured diaries, for example, where a researcher may be interested in how many times a diarist refers to a specific phenomenon of interest. Those interested in linguistic issues may also be concerned not just with the temporal narrative, but with the frequency of, and language used. It is also possible to adopt discourse analysis to the diary data (see also ► Chap. 50, “Critical Discourse/Discourse Analysis”). This may be particularly relevant for audio diaries where *how* an entry is recorded, and the tone of speech used in the audio diary, may be as important as what is said. In the main, however, the objective within semi- and unstructured diary method is to analyze the free-flowing data, whether written or oral. Following transcription of the data, this can be done using commonly used qualitative data analysis methods such as thematic or constant comparative techniques (see also ► Chap. 48, “Thematic Analysis”). Verbatim entries are thus coded, compared, and the data thematically categorized until no new themes emerge (Bartlett and Milligan 2015). The key purpose here is to identify themes emerging either from within an individual’s data over time, or across a sample of participants selected on the basis of their similar or differing characteristics. Where appropriate, a well-designed diary with a coherent precoding system (similar to framework analysis) can help to reduce the degree of editing and coding required. While audio diaries produce significant amounts of monologue and often contain background sounds, which may or may not be important to interpret, the basic approach to analyzing these data is the same (Pink 2009). The main difference between written and audio-diary data is the increased amount, and complexity, of the audio data and the researcher’s need to consider whether (or which) background sounds and information require interpretation.

While thematic and constant comparative analysis of diary data are useful, it is important to bear in mind that these forms of analysis rely on extracting small sections of diary data and reassigning by code or theme to achieve across person analysis. These approaches can result in the loss of two of the key strengths of diary data: the personal narrative and the temporality of that narrative. For this reason, some researchers reject the thematic approach in favor of narrative analysis that focuses on trying to make sense of the temporal story and conveying the meaning and contextual detail provided by the diary (Thomas 2007; see also ► Chap. 49, “Narrative Analysis”).

5.2 Analyzing Visual Diary Data

Diaries using visual data require a slightly different analytic approach. The more complex nature of visual diary data, where movement, body-language, setting, as well as the orally delivered diary data means analysis will be more time-consuming, requiring the researcher to do more filtering of what is/not required for the study (Noyes 2004, p. 203). Here, both moving images and spoken words need to be scrutinized and coded. Moreover, visual materials are suggestive, meaning that the researcher's whole body and sensory range is likely to be engaged in the interpretative process (Pink 2009). Hence, as Pink notes, the researcher's reaction to what they see and hear in the diary should be one of the first issues to reflect on in visual diary analysis. Identifying and noting those parts of a diary that the researcher finds most compelling (either positively or negatively), and why, adds another layer of meaning-making to the analysis (Allen 2009).

While photographic diaries produce images that are clearly meaningful to the participant, they too require a process of sifting and coding. This is usually done *with* the participant, selecting a sample for a more in-depth analysis (photo-elicitation/photovoice). Where this is combined with DIM (Diary-interview methods) approaches, the analysis of the photographs in the final interview can be seen as a facilitating coanalysis. In a multimethod study using video diaries, journals, and interviews to examine embodiment and everyday illness, for example, Bates (2013) analyzed her video-diary data in two ways. Firstly, each video diary was transcribed, integrated with the interview and journal data, and analyzed thematically. Secondly, by identifying categories and concepts *across* the different methods, she was able triangulate her interpretation of the video diaries and consider the diary data within a broader context.

The complexity and variety of data produced by video and photographic diaries means that some researchers aim to simplify the process by opting to analyze purposively selected aspects of the visual diary data rather than trying to make sense of the whole. In both Roberts's (2011) and Edinburgh et al.'s (2013) studies, for example, their analysis focused on what their video diarists *said* rather than trying to interpret the performative elements of the diaries; transcribing and analyzing the oral data in much the same way as audio-diary data is analyzed. In such cases, the rationale for using visual diaries may be less about the relevance of visual analysis, and more about the appropriateness of using this particular diary technique for the group or individuals being studied.

6 Strengths and Limitations of Solicited Diary Method

All research methods have their strengths and weaknesses – solicited diary methods are no exception. Critiques suggest they favor more literate and better-educated participants, and so it can be exclusionary to those with poor literacy skills or those with cognitive or physical limitations that hinder their ability to perform the task of diary keeping (see discussions by Meth 2003; Mackrill 2008; Cooley et al. 2014).

Yet, the wealth of highly successful solicited diary-based studies, undertaken with a wide range of individuals with different levels of literacy and so-called vulnerabilities, suggests this critique lacks validity. Solicited diary studies, for example, have been undertaken with people living with dementia, young children, young men with disabilities, older people, survivors of domestic violence, and those from minority ethnic groups, to name but a few (Bartlett and Milligan 2015).

Critiques are often based on a perception that the solicited diary relies solely on the (hand) written word. Yet, oral, visual, and pictorial techniques have often been used as an alternative to the written diary. The key is to take participants' strengths and needs into account and modify the diary method accordingly. Bartlett's (2012) use of audio and photographic diaries to explore the lives of people with dementia; Thomas et al.'s (2015) use of pictorial diaries with slum-dwelling mothers of children who are experiencing diarrhea morbidity in India; and Edinburgh et al.'s (2013) video-diary study of migrant girls who had runaway following sexual exploitation offer just a few examples. These types of studies illustrate how solicited diaries can be creatively adapted to meet the skills of those for whom written diaries may prove exclusionary. Furthermore, as we illustrate here, the growing availability of video and digital technologies means that solicited diary techniques no longer rely solely on gathering hand-written data and paper-based medium. As Cooley et al. (2014) note, semistructured video diaries can be particularly useful for overcoming the difficulties some people face in expressing themselves in written format. It also offers increased depth and freedom of speech with less reliance on researcher/participant rapport (Buchwald 2009).

A further strength of solicited diary methods is that they offer respondents space and time to think and consider questions/themes in private and the freedom to express intense sentiments (Cooley et al. 2014; Filep et al. 2015). Meth's (2003) diary study of domestic violence in South Africa is an excellent example of this. Rather inhibiting women from telling their stories, her diaries enabled space for women to record deeply personal descriptions of often traumatic life experiences. Diaries can thus be revelatory, in that they help researchers understand the embodied and the emotional, and can be used to delve into otherwise unreachable interpretations of social and physical experiences (Filep et al. 2015). Myers (2010) diary study with HIV-positive men, for example, illustrated how solicited diaries provided them with space to express thoughts and feelings that they would have found hard to do face-to-face. The longitudinal approach of diary techniques, and the provision of a situated "safe space" that allows for extensive individual and personal reflection, means that diary methods can provide rich tapestries of narratives with multiple divergent themes (Filep et al. 2015).

Numerous researchers have also noted the therapeutic value of diaries and the potential to enrich the diarists' lives (e.g., Meth 2003; Thomas 2007; Dwyer et al. 2013; Filep et al. 2015). Thomas (2007) maintains that not only can diaries feel therapeutic to the diarist, but they make diarists feel their opinions are valued and valid. Filep et al. (2015) go so far as to note that in their study, one diarist enjoyed the process so much he kept the original and submitted a photocopy.

7 Addressing the Limitations of Diary Methods

Where solicited diaries are used, it is important to bear in mind the action required on the part of the participant to produce the written, audio, or visual data and how this might affect the quality of that data. Diary-keeping relies on the participant's ability and motivation to complete the diary. Where motivation is low, this can result in attrition or gaps in the diary completions. Thus, Bijker et al. (2015) note the importance of personal interaction between the researcher and the diary respondents prior to the start of diary completion, as it creates a commitment to the research that motivates diarists to continue the diary. Milligan et al. (2005) also note that regular contact throughout the project (whether face-to-face, telephone, or electronic media) can help reduce noncompletion, particularly where a diarist may have stopped due to illness, holiday, or other personal circumstances; it can also encourage continuation of diary-keeping once the participant feels able to do so. Finally, Meth (2003) and others (e.g., Ulrich and Grady 2004; Boone et al. 2013) suggest that payment for diary completion can both encourage motivation and demonstrate recognition of the work of diary keeping.

Researchers have also commented that the dynamic or performative elements of producing a video diary or posing for an image as part of diary recording – and the importance of taking this account when analyzing the data. Noyes (2004), for example, in a video-diary study involving primary school children, noted how the participants tended to perform in front of the camera, particularly in the early stages of data collection. Others using video-diary method found that adult participants (particularly men) can be self-conscious about filming themselves (Roberts 2011). However, as (Buchwald 2009) note, just as with audio-taping an interview, the depth of (in this case) diary entries increases as diarists become more comfortable with the camera, and participants to get used to the diary-keeping process.

Others point out that solicited diary methods require the researcher to relinquish control of part of the research process (Mackrill 2008), offering less opportunity for the researcher to check on, and direct, the form and follow of data emerging or to probe interesting issues raised by diarists (Cooley et al. 2014). Critics have also suggested that the irregularity in the way diary data can be produced is a weakness, but this presupposes that other qualitative data produce more consistent and reliable data. Indeed, Mackrill (2008) suggests that *how* the diarist records data, what is and is not recorded, can also be a source of data in itself. Others suggest that there can be a selectivity to what data respondents choose to reveal in their diaries

But as Meth (2003) points out, this is true of any qualitative method. We would also add, that where these issues are important to the study, they can be overcome by combining diary methods with other techniques such as DIM.

A final issue we raise in this section is the potential for diary techniques to raise consciousness within the diarist of events/lack of events that have the potential to cause harm (Milligan 2001; Meth 2003). Because the researcher is not present during diary completion, s/he is unable to provide the same level of emotional support as may be able to do in face-to-face methods. Kenten (2010) has thus suggested that

where there may be risk of vulnerabilities being exposed in the diary-keeping process, it may be useful to use a DIM design as the postdiary interview can also be used to debrief the participant, helping to mitigate any potential discomfort caused by the diary-keeping process.

8 Diary Methods: Practical Examples

In this final section, we draw on practical examples of the use of solicited diaries from our own research.

The first study involved the use of solicited diaries as part of a mixed methods study designed to understand the well-being impacts of communal gardening for older people when compared with other social activities (Milligan et al. 2005). The diaries were designed to gather longitudinal data about activities and factors impacting on participants' health and well-being over time. The diary was structured as a brief booklet comprising: instructions for completion and return; a short quality of life survey; and an open text section with narrative prompts. Participants were asked to complete the diaries on a weekly basis and were encouraged to write as much or as little as they wanted – focusing specifically on what was important to *them*. They wrote about thoughts, feelings, and events in their everyday lives that they felt were connected to their health and activities. The project researcher kept a record of all submitted diaries and where a diarist failed to complete, she made contact to investigate why. This turned out to be crucial to the study, facilitating the building of a rapport between the researcher and the participants, providing support and encouragement, and enhancing completion rates. In total, 69 older people aged between 65 and 91 years completed the weekly diaries over a 30 week period. Accounting for attrition and noncompletion, we gathered 1609 diaries in total – a completion rate of 81%. This approach also gave us a better insight into reasons for noncompletion (largely due to illness or holidays) and encouraged continuation of the diary-keeping once the participant either regained their health or returned from holiday.

The diaries revealed not only the ups and downs of older people's health and well-being over a sustained period of time, but also their levels of activity and social connectedness. In particular, they highlighted the importance of family and friends in sustaining and supporting participants' well-being and activity – and in some cases how the stresses and difficulties of family relationships can have an adverse effect on an older person's well-being. "Lucy" (aged 68), for example, lived alone but wrote of the importance of her family in helping her through a period of illness. She wrote in her diary, "I am at last back to my normal fit and happy self. For a time I felt quite low, but thanks to the help and support of my daughter and her family, and to my own determination, I got over this." Conversely, Florence (aged 73) wrote of having a busy and active life despite her health problems, but woven through her diary accounts is a narrative of a difficult relationship with her 42-year-old adult son who lived with her. She wrote of how she found her son's controlling attitude difficult to deal with, and her increasing depression resulting from their regular arguments and

inability to live together harmoniously. Over time, her diaries revealed how her activities and social relationships were bound up in strategies to keep her away from what she describes as “the black cloud” hanging over her home (Milligan et al. 2005, p. 1887).

So while how people complete diaries can be very different, from the detailed reflective and emotive entries to the brief factual account. Yet, despite these differences in the length and depth of entries, the diaries gave us detailed longitudinal insights into participants’ lives that enabled us to draw out the interconnections between health, environment, and everyday life for older people.

The second study relates to the use of diary interview method to investigate the rise of activism among British people with dementia (Bartlett 2012). Sixteen people with dementia who were engaged in some form of social action or campaigning related to their health condition were recruited to the study. Participants were asked to keep either a written, photo, or audio diary of their activities. Five participants kept a photo diary, three kept a written diary, and one kept an audio diary. The seven remaining participants kept a combination of one or more of the diary methods, but no one chose to keep all three. Everyone kept a diary for about one month.

A range of diary techniques were used in this study to enable people with dementia to participate; it was recognized that not everyone would want or be able to write, or take photographs, or speak into a voice recorder, thus people had a choice. The approach enabled participants to have greater control over the content and pace of data collection than traditional data collection methods allow. For example, the audio diarist took his time to find the right word – he said “worm” instead of “word” – and switched the recorder on and off, presumably to prepare to speak. His finger controlled the record button, not the researcher (Bartlett 2012). Other participants supplemented their diaries with artefacts they had collected during their campaigning activities, such as reports and brochures. Virtually, all the photo diarists took photographs of how and where they spent their leisure time. All of which is to say that diary-interview method enabled people with dementia to not only participate in this study, but to participate on their own terms.

Finally, it is important to note that there were certain drawbacks to using diary interview method in this study involving people with dementia. Notably, the process of keeping a written diary evoked a certain amount of anxiety for some participants; some individuals were not sure whether what they were doing was “right,” others did not like reading back what they had written (Bartlett 2012). Researchers are therefore advised to highlight this as a potential risk in the study’s participant information sheet.

9 Conclusion and Future Directions

A growing number of researchers are beginning to recognize the potential added value of solicited diary method in social research – whether as a stand-alone method or as one element of a multimethod study. We foresee that this will continue to grow in strength and that, of itself, will trigger further innovative developments.

However, it is perhaps the rise of technologies, especially capture and digital technologies, and their integration into research methods that hold the most promise. These developments mean that researchers will increasingly find themselves having to engage with, and adapt to, the digital culture. The growth of ubiquitous technologies, smart phones, tablets, and so forth means that we are shifting toward a scenario in which the research equipment required for undertaking solicited diary research may be significantly simplified. The capability is now there for research to be undertaken through one device that has multiple capacities and features to facilitate both video, audio, and electronic written diary keeping. Such devices will become an increasingly common part of daily life within many households, particularly in high-income countries. We should not forget, however, that access to, and familiarity with, digital technologies can still raise issues of access for those who are less affluent (including those living in less developed parts of the world) and those whose physical, sensory, or cognitive limitations may require specially adapted equipment.

The acceptability and expectation of self-disclosure practices evidenced through blogging, Facebook, and the rise of the “selfie” is re-energizing the practice of diary keeping but in much more public and interactive ways than we have seen in the past. Weblogs, for example, are simultaneously public and personal diaries. They are intended to be read and to provoke dialogue with others. This presents opportunities for researchers to solicit online diaries or to analyze existing online diary data in ways that have not previously been possible. Arguably, then, the boundaries between solicited and unsolicited diaries are blurring due to web-based applications and practices such as blogging and Facebook, presenting researchers with challenges to the traditional notions of solicited and unsolicited

Finally, given that human relationships are becoming more mobile and interconnected (Urry 2000), it is important that researchers develop and use methods that have some synergy with the day-to-day practices and experiences of their participants. For example, email diary studies, such as Jones’s and Woolley’s (2014) study of the effects of the London Olympics on daily commuters, are likely to become more commonplace in the future. Whatever direction diary methods take in the future, it is imperative that teaching and texts on research methods move beyond their traditional focus on standard qualitative techniques, to ensure new researchers are aware of the significant potential of adding solicited diary methods to their methodological toolbox.

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Teddy Diaries: Exploring Social Topics Through Socially Saturated Data

84

Marit Haldar and Randi Wærdahl

Contents

1	Introduction	1466
2	What Are Teddy Diaries?	1466
3	Socially Saturated Naturally Occurring Data	1467
4	The Two Contexts: Home–School Communication and the Comparative Analytical Context	1468
5	Conclusion and Future Directions	1474
	References	1476

Abstract

Teddy bears with diaries are common pedagogical tools for home-school collaboration. In this chapter, we use three analytical examples comparing teddy diaries from Norway and China to demonstrate how these diaries give unique access to the display of family life. Because the diaries circulate not only between the school and the family but between families, each family influences the other in how they write their entries. This social process saturates the diaries with the norms, values, and ideas of the social context. Comparing and contrasting diaries from two different contexts adds to the richness of each dataset, as it illuminates the things that we take for granted and the things that are there that we do not talk about. By this methodological demonstration, we wish to challenge two hegemonic positions in qualitative methods and show that you do not have to “be there” to get close to lived life and you do not have to “speak to people” to get trustworthy data about the social. This kind of data is easily assessable for research with the consent of schools and families, and they are easy to initiate in schools or any institutions with groups of some permanence.

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1465

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Display of families · Participatory data · Family life · Comparative analysis · Data saturation · Teddy diaries

1 Introduction

In this chapter, we demonstrate a method for exploring display (Finch 2007) of family life. The significance of this method lies in the combination of using naturally occurring data that have been socially saturated by circulating among families and comparing these data with a second set that has been socially saturated to an equal extent in a different context. When datasets from two of these contexts are compared, each dataset informs the other, enriching and elaborating the data.

Using four examples from teddy diaries produced in two very different contexts, we demonstrate how the combination and comparison of socially saturated naturally occurring data facilitate discovery of taken-for-granted traits of everyday family life. The examples are comparisons between schools and families in the Oslo metropolitan area in Norway and in urban Beijing, China. These contexts are apparently very different, but the comparative context does not have to be as different as this to yield revealing results.

This approach to contemporary family life challenges two hegemonic positions on qualitative methods to obtain trustworthy data: the ethnographical notion of “being there” (Geertz 1973; Clifford and Marcus 1986; Marcus 1995; Moore 1999; Davies 2010; Liamputtong 2013) and the authenticity of the spoken word gathered through personal interviews (Gubrium and Holstein 2002; Kvale 2007; Denzin and Lincoln 2011; Hammersley 2013; Serry and Liamputtong 2017). As a result of these hegemonic positions, texts receive a secondary status as data.

2 What Are Teddy Diaries?

Teddy bears and teddy diaries were introduced as a pedagogical device in Norway after the school reform of 1997 to ease the transition between a student’s family and the first year of school. Each new school class gets a teddy bear that will visit every child’s home in turn, carrying a diary where the bear’s experiences in the children’s home are recorded. During the first year in school, the teddy will visit each pupil several times. The diary has an introductory page with a greeting from the teddy bear that usually says something like this:

Hello, my name is Teddy and I am a special friend of this class. This is my book. I will be very happy if you write and draw in my book about the things you and I experience together. I am sure that your Mommy or your Daddy can help you.
Warm regards,
Teddy

The diary entries are written by the children, or by the children together with their parents, and must be read as a negotiated textual description of what the family regards as a valid account of their activities on any given day. Most importantly, the entries represent a choice of topics that they consider worth mentioning to classmates, teachers, and other families. Teachers and classmates share the entries, as well as the families who are next to receive the book and the teddy (Halder and Wærdahl 2009; Wærdahl and Halder 2013; Halder and Engebretsen 2013; Halder et al. 2015).

3 Socially Saturated Naturally Occurring Data

Naturally occurring data are characterized by being derived from texts, social situations, or processes that are not initiated by a researcher (Geertz 1973; Silverman 2011). Thus, it is typical of such data that they are not communicated to the researcher in a controlled setting, but one that would occur regardless of researcher involvement. An important criterion for natural occurrence is that the researcher's influence on the data is minimal. The researcher's preanalytical questions, glances, or facilitation should not influence them.

Another important feature of naturally occurring data is in their association with the context. The data should exist in their natural context, so context is highly relevant for the data (Graue and Walsh 1998; Halder and Wærdahl 2009) and may be significant in several ways. What people say depends on the situation and to whom they are talking. What a person writes reflects both where it is written and for whom it is intended. In the case of the teddy diaries, it is crucial that they are filled with stories written by children and their parents in collaboration. Another important trait is that the authors of the diaries are aware that other families, classmates, and teachers will read what they have written. Thus, the natural context for these texts is home-school correspondence. They are simple, probably because they convey everyday events that everyone can recognize. They should engage other children in the class, and they are probably written in some haste, as this is an obligatory task performed from 1 day to the next. These texts would be different if they were written as private diaries, letters to someone's grandmother or replies to a household survey.

Low researcher influence is a prime quality in naturally occurring data, as it indicates low contamination of the "natural." This is not particularly important in the case of the teddy diaries and is in fact almost the reverse. The more that readers and writers have been involved in the contextualization of the data, the more saturated it becomes with the social subject matter we seek (Lareau and Shumar 1996). Every family who writes in the diary and reads the work of other families, every school class and every teacher and even the researcher leave their marks on the text as well as on the interpretations of the text. This social impact on the data is desirable and is a type of influence that researchers are unable to exert on the data on their own.

The diaries contain parent-assisted correspondence between 6-year-olds, written with the knowledge that there is a normative audience of teachers and other parents. All families except the one that receives the diary first know what others have written. All families except the last one know that other families will read what

they write. Teddy diaries can, thus, be read as an exchange of normative everyday standards between different homes and between home and the school public. Researcher effect is therefore relatively low, but the impact of the social, cultural, and contextual on the data is very high. What we actually learn from these diaries are topics that a researcher would not necessarily ask about, yet that convey highly saturated information about norms and values and those that are socially accepted (Rose 1989; Dean 2009). We learn what different families choose to publish about small and large events in an ordinary day. Where people are, who does what, who is with whom, how they get along together, or what they do alone can be recorded in the diaries. In many ways, it could be said that the most important qualities of these data are those with which they are imbued by circulation between informants before they reach the researcher. What is exchanged and reinforced by the evaluation of others becomes the most interesting feature of the material. Teddy diaries can be understood as a joint production of what is ordinary (Sacks 1984).

4 The Two Contexts: Home–School Communication and the Comparative Analytical Context

The first context of these diaries is home–school communication. We discovered teddy diaries as mothers when our children were first graders in a Norwegian primary school. In 1997, important school reform in Norway lowered the school admission age to 6 years, and it became crucial to prepare schools for encounters with 6-year-olds. One pedagogical measure was the introduction of a class teddy bear and the teddy diary. We were the first researchers to see them as suitable data material for a sociological analysis of families with children and as providing unique access to the norms and ideals of family life (Haldar and Wærdahl 2009). Because one of us (RW) had planned fieldwork in China, we were intrigued by the possibility of persuading some Chinese families to produce texts about normal life in China, without the researcher even being present. We decided to try the method in Beijing. Chinese teachers welcomed the concept of a class teddy bear equipped with a travel diary was with such great enthusiasm that ten bears went on home visits, and we received reports from nearly 30 families in Beijing for each of the teddies.

As a result, we had two sets of data. The first was from Norway where we contacted two schools in the Oslo area, and were given access to 16 diaries with 319 stories collected in the period 2006–2007. The second was from Beijing, where the process of writing diaries was initiated by one of the authors, driven by the schools and overseen by the teachers. In total, we had ten diaries from China with 284 stories collected from six schools within 3 months in 2006. These collections of diaries gave us analytical access to the normative environments that mold childhood and family ideals in Norway and China.

The other context that is important for the interpretations of teddy diaries is the comparative analytical context (Lamont and Thévenot 2000). By comparing texts written in two contrasting natural contexts, we are able to see what stands out as unique in each of the contexts, as well as obvious facts of which we are oblivious.

This acknowledgment can be transferred to all types of comparisons. The features that stand out as special only do so when we know what constitutes ordinary life and what is taken for granted in a context: The commonplace is often discovered to be common only when something unusual occurs (Lamont and Thévenot 2000).

Below we provide four examples to demonstrate the possibilities of this method. We have chosen examples where comparison between the two datasets has either made the data richer and more interesting or revealed something we might otherwise have overlooked.

Example 1 Developing a collective voice

When teddy diaries are circulating among families, a kind of genre or a script for writing entries is formed. In Norwegian diaries, we see that the posts take the form of a logbook of daily activities. These contributions are stories with a cast of characters who do activities together, often with a rapid sequence of events. A whole range of activities, often outdoors, are listed, with many birthday celebrations, parties, enjoyable moments, or play situations.

On Saturday we went to the cabin. We had to drive both car and boat. All but Teddy were wearing a life jacket. My cousin, who is twelve and a half years old, came with us. When we arrived we went for a swim, even though the water was cold. We jumped on the trampoline and we played cards. We also went into the woods and we visited some neighbours. On Monday we went home in time for football training. That was good, because Teddy and I were invited to come stay with Anne, and we thought that was great (. . .).

The expressed ideals are to spend much time outdoors, to be together, to have fun and not least to experience these things as “cosy.” These ideals are repeated and reinforced as the teddy diaries circulate between families and the school. Each story almost surpasses the previous one in its cosiness and range of outdoor activities.

When we read the Chinese teddy diaries, we see a different genre evolve. Here, diaries are more contemplative, with thoughts and reflections written down. These stories, like the Norwegian ones, are chronological. The teddy bear is given a warm welcome and is introduced to family members as a valued guest, and it is emphasized that the child is special to be honored by a visit from teddy. This provides an opening to describe the splendid qualities of the child. The stories usually end by reporting how hard it is to say goodbye. Between welcome and farewell, they talk about routines, duties, food, and studies, but also about fun and intimate conversations. Thoughts, feelings, evaluations, and educational advice are the most frequent elements of the Chinese diaries. The circulation of the texts reinforces the ideals of honor, praise, and duty.

I wish I could bring Teddy home every day (. . .) when Mum picked me up after school I introduced her to my special friend, Xiao Xiao. Then Mum was happy and proud of me. ‘You’re awesome! You just have to continue to study hard and work so that Xiao Xiao will come home to you every day!’ When we got home I put the teddy bear on the bed, and I took its paw and we agreed that it would help me do my homework. (. . .) I didn’t dare get distracted when Xiao-Xiao was watching me. (. . .) My Dad and Mum said ‘you should be like Xiao Xiao every day, dutiful, that’s good’.

Different genres develop in the Norwegian and Chinese diaries, and there is an interesting genre aspect that underlines how circulation works to reinforce values. The stories in the Chinese diaries become increasingly alike as the diaries are filled. This is in great contrast to the Norwegian diaries, where the extraordinary and peculiar are the normative genre. We recognize this from the contrasts between one story and the next. In the Norwegian teddy bear stories, it seems to be of the utmost importance to show that the bear has experienced something very special in the child's home, not just the same as in the one before. This does not mean that norms are absent in the Norwegian stories, while they are present in the Chinese ones. It means that while sameness is a strong norm in the Chinese diaries, uniqueness trumps sameness as a norm in the Norwegian diaries.

Both sets of diaries demonstrate how circulation reinforces the values of the context (Rose 1989; Dean 2009), but it is also interesting to note that these values would be hard to see without the comparative element.

Example 2 The significant routines

The texts provide access to conventional family life. Families most likely deliberately choose not to write about topics that are unpleasant or embarrassing. However, events that a family would like to acknowledge can be described in detail (Gubrium and Holstein 1990; Finch 2007; Morgan 2011).

The obvious cultural content in both the mentioned and the omitted topics is easier to capture through comparison, without which it would be particularly difficult to discover what is missing. It is the unique combination of comparative analysis and socially saturated naturally occurring data that creates this form of data on the obvious. This may be illustrated by the descriptions of obvious activities that are worth mentioning and by those that are omitted.

As a cuddly toy, the teddy bear belongs to the intimate sphere in both Norway and China. In the diaries, we read much about sleeping and bedtime routines. In Norway, sleeping is often described as occurring almost as a result of exhaustion after a day filled with activities, often physical and often outside. One teddy bear put it this way: "Now I'm really tired, so Ola and I are off to bed, a little late because of the birthday party." In another entry, the bear says: "It has been a busy weekend, and I've experienced a lot. Now I'm tired, and Felicia and I are going to bed." Both these quotes say something about the importance of going to bed after an active day. The sleep is well deserved. Going to bed "on time" also seems to be an important norm. In the first case, we see this norm expressed as an exception: *It has become especially late*. In other words, Ola usually goes to bed earlier.

The importance of sleep is also reflected in the Chinese diaries, but the routines around sleeping are different. In the Chinese diaries, they do not go to bed exhausted, but bring certain activities with them into the bed, where there is an element of preparation for the next day. It is common to do learning activities just before or after going to bed. A Chinese child writes:

I went through my English homework again, so I kept Xiao Xiao in my arms while I went to bed. I told Xiao Xiao that tomorrow I will have a language test, so I should rest well before that.

Another Chinese child writes:

Last night I kept teddy bear in my arms while I slept. Today when I woke up, I let the bear listen to me reading English. At noon, after lunch, I took the teddy bear with me for an afternoon nap.

Where children sleep and with whom may also be different. As we have seen in the above cases, the teddy often sleeps in the child's bed. However, by comparing sleep routines in the two datasets, we became aware that in the Norwegian diaries it is not uncommon for the whole family to go to bed together in the parents' bed, as in this case:

Teddy, Mum and I went to bed in Mum and Dad's bed, where we slept well, all together.

In the Chinese diaries, there is no mention of sleeping in the parent's bed, but the teddy sleeping in the arms of the child is common. Moreover, they sleep together several times a day, with the bear taking a nap with the child after school, after dinner, or before homework. Sometimes they sleep in the car on the way home from school, if they have far to travel. In Norwegian diaries, sleeping is never mentioned as anything but a night-time activity.

In both Chinese and Norwegian diaries, sleep is important, but the importance attached to sleep in the two contexts is different. Sleep is primarily described as an ending to the day in both places, but while the Norwegian entries describe sleep as a necessary rest after a long active day, the Chinese stories describe sleep as a preparation for what comes after waking; it occurs not only at night but also at other times of day.

Example 3 Analyzing what is (not) worth writing about

While sleeping is important for teddies in both Norway and China, it is noteworthy that none of the Norwegian children reports resting after school, or before homework. In fact, in the Norwegian diaries, no one talks about doing homework at all. This does not mean that Norwegian children do not do homework; they just do not consider it worth mentioning. Norwegian six-year-olds may have less homework than their Chinese counterparts, and the teddies may go on more weekend visits in Norway. Nevertheless, it is a little surprising that in the context of a home-school communication tool, they do not find it important to mention that they are doing homework, even on weekdays.

The Norwegian diaries never mention homework. However, we did not notice this until we made the comparison with the Chinese diaries. The lack of homework in the former becomes evident when comparing with the latter, in which homework occurs all the time.

I showed Xiao Xiao to Mum, and she said, 'Why did you bring this home with you?' I said, 'I've been so attentive in class and listened to the teacher, so she rewarded me.' I also showed Xiao Xiao to Daddy, he was also very happy, praised me and said I was good (...). After dinner I wanted to study. I placed Xiao Xiao beside my desk. Xiao Xiao sat quietly and watched me study, so we read English together. Then we should sleep. I washed my face and brushed my teeth with Xiao Xiao beside me. It looked like Xiao Xiao was saying, 'You are a child who is really concerned about hygiene'.

Another virtue that appears, especially in the Chinese diaries, is good hygiene. This is yet another example of how comparing two datasets reveals points that are not mentioned in one of them. In the Norwegian diaries, nobody mentions that they wash or brush their teeth. Obviously, this does not mean that Norwegian children do not; just that it is not seen as important enough to mention. However, the teddy bear is washed in the laundry or has a shower in the stories from both countries.

Comparison sometimes reveals obvious points from what is omitted from the stories. At other times, we understand that something is significant because it is mentioned often and described in detail. The numerous activities and relationships mentioned in the Norwegian diaries are an example. Here, children attend sporting events and competitions, particularly soccer and handball. They go to the cinema and the swimming pool and have grandparents visiting. Overnight visits with a friend are frequent. They regularly travel to their cabins, feed the ducks or other animals, or go hiking in the woods. In general, these are stories about being outdoors frequently, and there are many people in them. Some excerpts from Norwegian diaries illustrate what is typically believed to be important and worth writing about in a Norwegian context:

On Sunday, Teddy got to taste blueberries. Moreover, we found three orientation posts in the north woods. Teddy enjoyed the walking tour and it was nice that both (maternal) grandmother and grandfather came along for the trip as well as my aunt and cousin.

On Saturday, we picked mushrooms in the woods, during lightning and thunder, but it was okay for Teddy. On Sunday, the rain was really pouring, so we only made a small trip looking for mushrooms in Birkelunden (the city park).

Again, the contrast reveals the importance of things that seem mundane at first glance. In the Chinese diaries, there is no child who is described as sweaty or tired after physical activity, no mischief is described, and there are no overnight guests besides the teddy bear. In the Norwegian diaries, homework is never written about, and there is no brushing of teeth or praising the obedient child, his/her excellence, or virtues. The comparison between the two datasets provides a key to understanding what is meaningful in a given context, from something being described both extensively and in detail, and from being particular to one context when it is absent in the other. Knowledge of the social context is crucial to interpret omissions (Haldar et al. 2013).

Example 4 Bear qualities

Field researcher Cato Wadel (1991) emphasizes informants' awareness of identity when they tell us something, show us something, or give us access to something. He writes that one should be "a sociologist on oneself" because the roles attributed to the researcher in the field indicate important facts about the field (Wadel 1991: 59). Although researchers are not present in the field when we use teddy diaries, and the usual researcher effects are minimal, there is still a figure following the diaries and the texts from home to home, namely the teddy bear (Borovski et al. 2016).

In both China and Norway, the children find it necessary to explain much to an uninformed teddy bear. Moreover, the teddy bear is given many roles, just as a researcher would be. Teddy can be described as a friend, a stranger, a teacher, or

someone who needs training. The teddy bear can also be a catalyst of events, feelings, and actions. In this section, we illustrate examples where Teddy is given the role of either instructor or student. Through these descriptions, we gain access to both the ideals and moral imperatives of bringing up children (Bernstein and Triger 2011; Chambers 2012).

In the Chinese texts, we see that when parents write the entries, they may use the teddy bear to provide clear moral advice to the child, or assign the teddy bear an important role as a bearer of good and desirable properties. Here is a Chinese example:

When I see Teddy's simple and honest look, I think of an old proverb that says: 'To be human means that one must be kind and honest' (...) As the teacher takes care of us, we must take care of the teddy bear; let Teddy grow up together with us and be a healthy, happy, honest, hardworking and good child.

If we compare this with the Norwegian diaries, we never encounter explicit moral advice. However, moral imperatives are still implicit. For example, there are several stories where the teddy bear has eaten too many sweets and suffers from stomach-ache.

Properties ascribed to the teddy bear can be interpreted as stories about the child's abilities, often in the form of what might be expected from a child or what children are expected to either outgrow or learn. For example, there are teddy bears who are afraid of going to the dentist, teddy bears who are too tired to walk and get to ride on Dad's shoulders, and there are teddy bears that do not finish their food. Not infrequently, the teddy bear is bored – and most of all – tired. To simplify the contrast, we can conclude that being exhausted has a high moral value in both countries. However, while Norwegian children should be exhausted from outdoor activities, Chinese children should be exhausted from doing homework.

Using the teddy to talk about being afraid or refusing to eat is also a way to acknowledge a child's feelings. Because it is not always easy to voice aloud that your child is tired or afraid, or to admit to behavior that is inappropriate for the child's age, the bear adopts the vicarious role of the child for such descriptions. When the class reads aloud from a diary, the other children empathize with the weary frightened teddy, and the child him/herself is not directly affected by the description. In this role, the bear functions as a catalyst for thoughts and feelings the families (children or parents) may not otherwise have talked about. When the bear is told to do things properly, or it has difficulties mastering desired skills, it is no major issue to discuss it, while parents would not describe their children in the same critical way. Here is an example from a Norwegian diary:

Teddy and Thomas were securely strapped into the back seat, and we headed for the mountains (...) On Sunday, all the children including Teddy set off early. Teddy borrowed some sunglasses and got sunscreen on his nose; the sun is harsh in March! We went skiing with sticky wax under the skis. We did not go particularly fast. Teddy struggled terribly in the snow. We suspect that he has not skied very much before. Maybe his family is Danish?

In the Chinese diaries, we read that teddies are well instructed by the children, with many clear and direct pieces of advice about what the bear should do and how it should behave, often expressed as coming directly from the child. Despite all the well-behaved teddies in the Chinese diaries, there are also bored teddies, impatiently waiting for the child to finish their homework or activities in which bears are not allowed to participate. The latter can be interpreted as examples of venues where it is inappropriate to take a friend or a pet, such as for extra lessons in English. We also find examples of naughty teddies, perhaps reflecting annoying behavior that one would not ascribe to the child in such a text. Here is an example of a Chinese teddy bear who apparently slept a little too long in the morning.

Today I woke up early and wanted to play with the teddy bear. But when I looked, I saw that the bear was still asleep. I didn't have the heart to disturb him, and thought I would have to wait until he woke up by himself, and then play with him. He is really a lazy little bear. Ah!

Ideas on education and morality can be deduced from such narratives as both direct exhortations and descriptions of desirable properties. However, ideas can also be reflected in how the teddy bear is treated or described according to what are considered good and bad qualities in a teddy bear. The teddy bear can act as a conduit through which to convey clear expectations to a child without appearing authoritarian. Indirectly, the teddy bear takes on the position of the child (James 2007).

Again, we see that comparison adds an extra dimension to interpretation, and that ideals expressed in both datasets become even more apparent in contrast. The ideal of the active and playful Norwegian child is reinforced in contrast to the learning and time-structured Chinese child. Similarly, the obedient Chinese child is reinforced in contrast to the Norwegian child who is always negotiating.

Although the effect of the researcher is minimized in these data, the effect of the teddy bear is significant. The teddy bear is assigned roles, abilities, and expectations, and it is the catalyst for events that do not necessarily occur every day. For example, if the teddy bear is assigned the role of an important guest, there are descriptions of how guests are received. If the role ascribed to the bear is that of a new member of the family, or a close friend, there is access to other kinds of information, and perhaps more intimate everyday events and descriptions.

5 Conclusion and Future Directions

In studying contemporary life through qualitative methods, “being there” is the ethnographer’s trademark, and in the sociological toolbox of qualitative methods, personal interviews have achieved a nearly hegemonic position (Silverman 2007; Liamputtong 2013).

In this chapter, we have sought to refute the common idea that truth lies within the individual, as the use of in-depth interviews would suggest. Using simple teddy diaries, we have shown that social research ideals do not have to delve deeply into an individual to reach the “truth.” Significant insights into social situations can be found

on the surface, in the obvious, and in information easily shared with others. Simple notes from a family's daily lives are rich in socio-cultural awareness of respectable family lives.

We have also demonstrated that the researcher's presence is not necessary. The teddy bear's unspecified nature makes it possible to attribute infinite roles and inclinations, roles that a researcher could never have played. The teddy can be a guest, a little brother or sister, a mischievous child, an ignorant person, someone to be boasted about, or someone to be raised. These assignments to hybrid roles provide important social information.

Most importantly, the data in their entirety show that texts have unused potential. The most common view of texts is that they are not life itself, but they refer to life. However, as we see it, much social life occurs textually, and today probably increasingly so. Social media are full of textual realities and brimming with significant integrative mechanisms and subtle logics of power. Seemingly insignificant texts such as teddy diaries may be very powerful. Our everyday lives are clearly present in such texts.

In this chapter, we have argued that teddy diaries, as naturally occurring data, are a good source of knowledge about the norms, values, and ideals in the social context we wish to examine (Griffin 2007). Circulation and context add richness to the data from teddies and their diaries. The combination and comparison of naturally occurring data help us to discover the familiar. When combined and contrasted, each dataset becomes richer and more nuanced, and together they provide the contrast needed to illuminate the taken for granted.

The diaries contain short simple stories of everyday life, about common knowledge and topics that are easy to discuss. Circulating between readers and writers in a delimited context, reinforcing superficial truths, the diaries are socially saturated with the self-evident. For precisely this reason, they convey significant information about the ideals and taken-for-granted qualities of everyday family life.

Since we discovered Teddy diaries as a rich source of information about families in our own social context, we have both initiated and collected similar diaries from other places in Norway as well as from other communities in other countries around the world. The fact that we can obtain highly socially saturated data with low researcher interference is one of the features that make these data attractive for research. Not having to be there for every interview, observation or participation makes it additionally interesting because we can cover more families without extra researcher efforts. Moreover, by not being there, we give the families an opportunity to choose what to write about, and increase the likelihood of answering questions about their everyday life that we have not even thought about asking in an interview.

This kind of data is easily assessable for research with the consent of schools and families, and they are easy to initiate in any institutions with groups of some permanence. Having had numerous materials to compare with, we have experienced how rich originally "thin descriptions" in a diary may be. As for others aiming to use diaries in their research, we would like to underscore that comparative cases do not need to be transcontinental and very different as in our case here. Two communities close by each other may also be challenged through comparison that will enrich each

dataset. Finally, we find these kinds of data valuable for family research, to reach a negotiated collective voice of a family, and not the perspective of a singular voice as, for example, a parent's understanding of a child.

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Qualitative Story Completion: A Method with Exciting Promise

85

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Contents

1	Introduction	1480
2	Theoretical Lens	1481
3	Benefits of SC as a Data Collection Method	1482
4	Suitable Research Topics and Questions in SC Research	1484
5	Stem and Study Design in Story Completion Research	1484
6	Completion Instructions for SC	1487
7	Asking Additional Questions in SC Research	1488
8	Sampling in Story Completion Research	1488
9	Data Collection and Ethical Considerations in Story Completion Research	1489
	9.1 Piloting in SC Research	1490
	9.2 Ethics in SC Research	1490
10	Analyzing Story Completion Data	1491

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10.1	Story Maps	1491
10.2	Frequency Counts	1493
10.3	Analysis Approaches to Avoid	1493
11	Conclusion and Future Directions	1493
	References	1495

Abstract

This chapter introduces the story completion (SC) method of collecting qualitative data, a novel technique that offers exciting potential to the qualitative researcher. SC involves a researcher writing a story “stem” or “cue” – or, more simply put, the start of a story, usually an opening sentence or two – and asking the participants to complete or continue the story. Originally developed as a form of projective test, the use of SC in qualitative research is relatively new. The authors comprise the *Story Completion Research Group*, a group of researchers that have come together to share their experience of using and further developing the method. This chapter explains what SC offers the qualitative researcher – including choices about the “best” epistemological lens and analytic approach for their research question, the potential to collect data about sensitive or taboo topics and to access socially undesirable responses, as well as the possibility of research designs that allow comparisons (for example between male and female respondents). This chapter also provides key guidance, such as what constitutes an appropriate research question, and sampling and design considerations. As a recently developed method, SC has fewer published research studies than some of the other research methods covered in this volume. For this reason, the chapter aims not only to provide a description of the method and recommendations for how best to use it, but also to explore some of the unresolved theoretical and practical questions about SC as well as to suggest future directions for SC.

Keywords

Story-completion · Qualitative methods · Data collection · Innovative

1 Introduction

Story completion (SC) involves a researcher writing a story “stem” or “cue” – or more simply put, the start of a story, usually an opening sentence or two – and asking the participants to complete or continue the story. Most forms of qualitative data collection involve the gathering of direct self-reports, so SC offers the qualitative researcher a radically different approach to data collection, and one that we think holds much potential.

SC originally developed as a form of projective test, for use by psychiatrists and clinical psychologists, to assess the personality and psychopathology of clients (see Rabin 1981). Projective tests involve asking people to respond to ambiguous

stimuli, such as inkblots, as in the famous Rorschach inkblot test (Rorschach et al. 1921/1998). The assumption is that because the respondent cannot know unequivocally what the stimulus “is,” they have to draw on their own understandings to make sense of it, and “fill in the blanks.” In doing so, as the theory of projective tests goes, the participant reveals things about themselves that they may not be conscious of, or would feel uncomfortable revealing if asked directly about. Projective tests are rooted in psychoanalytic theory (Rabin 2001), which assumes that large portions of the self are blocked off to consciousness, and thus unavailable to both clients and clinicians through conventional means, such as self-reported accounts. Projective tests are thought to tap into this “blocked off” information, providing what Murray (1943/1971, p. 1) described as “an x-ray picture of [the] inner self.”

Projectives have also been used as a research method, for example, in consumer and business research (e.g., Donoghue 2000; Soley and Smith 2008) and developmental psychology (e.g., Bretherton et al. 2003; George and West 2012). Projectives as a research technique (such as SC) have typically been used in *quantitative* designs, with complex coding systems developed to allow researchers to iron out the variability in individual responses to the projective stimuli, and turn the rich narrative detail into numbers and categories suitable for quantitative analysis.

Because it is assumed that projectives reveal “hidden truths”, those who use projective methods in this way rely on a (post)positivist epistemology, taking an essentialist stance on the person and on the data. Such an approach does not sit well with many qualitative researchers, and in the rest of this chapter an alternative approach to using SC is elaborated, one which is grounded more firmly within a qualitative paradigm.

SC was first used in qualitative research in a 1995 study by feminist psychologists Celia Kitzinger and Debra Powell. They used SC to examine how 116 male and female undergraduate students made sense of infidelity in the context of a heterosexual relationship. They suggested that it was not necessary to read the stories as (only) revealing the psychological “truth” of the respondents: “researchers can instead interpret these stories as reflecting contemporary discourses upon which subjects [sic] draw in making sense of experience” (1995, pp. 349–350). This approach to SC is a social constructionist one, rejecting the idea that it is possible to access “real” or “true” feelings or thoughts, and assuming instead that realities are discursively constructed (Burr 2003). Kitzinger and Powell (1995) illustrated the differences between essentialist and constructionist readings of SC data by contrasting two different readings of their data. An essentialist reading would see the data as revealing any gender differences in “attitudes” to infidelity; a social constructionist reading would make sense of the data as replicating various (gendered) discourses about the meanings of infidelity for men and women.

2 Theoretical Lens

We contend that qualitative SC can be used in both essentialist and constructionist qualitative research, and this theoretical and conceptual flexibility makes the SC method eminently adaptable to a range of research questions and approaches to

qualitative research! The aim in this chapter is thus to hand researchers the tools from which to choose which theoretical “lens” to apply to their data.

How might different theoretical lenses impact on SC research? Epistemology has implications at both design/data collection phases, but most vitally at the analytic/interpretative phase. In essentialist qualitative SC research, the data are assumed to represent participants’ real perceptions of a phenomenon. US psychologists Jennifer Livingston and Maria Testa (2000), for example, used qualitative SC within an *experimental* design in which the female participants were given alcohol, a placebo drink or no drink, to explore women’s perceptions of their vulnerability to male aggression in a heterosexual dating scenario. The researchers asked women to imagine *themselves* as the female character in their story and to write in the *first person*; they treated the women’s responses as representing their true beliefs about this topic. An example of constructionist SC research can be found in feminist psychologist Hannah Frith’s (2013) research on orgasmic “absence”, where she treated SC data as capturing the cultural discourses available to participants. Frith’s analysis explored how the stories drew on and reinforced various gendered discourses, including women’s responsibility to be sexually attractive to maintain men’s sexual interest and the notion that men’s sexual desire is unbridled and easy to satisfy. Contextualist research, which sits somewhere between essentialism and constructionism, and where multiple truths or situated realities are understood to exist within particular contexts (Braun and Clarke 2013), is also possible using SC. However, at the time of writing, there are no published studies exemplifying this approach.

3 Benefits of SC as a Data Collection Method

Theoretical flexibility is only one benefit that SC offers the qualitative researcher – there are many others:

1. ***SC gives access to a wide range of responses, including socially undesirable ones***: SC offers an alternative to approaches that ask people directly about their views and understandings of a particular topic, instead asking them to write about the *hypothetical* behavior of *others* (Will et al. 1996) or how they would feel in a *hypothetical* situation. When participants are prompted to write hypothetically, they do not have to take ownership of, or justify, their stories in the way they would if they were being asked directly about the topic. Therefore, they are more likely to “relax their guard” and engage with the research topic with less reserve. This gives SC the unusual advantage of breaking down the “social desirability ‘barrier’ of self-report research” (Moore et al. 1997, p. 372).
2. ***SC ideally suits sensitive topics***: SC also offers a particularly accessible way for participants to take part in research, because it does not necessarily require personal experience of the topic. The use of hypothetical scenario story telling also means participants are slightly “removed” from the topic. This makes SC *especially* useful for exploring sensitive topics – if questioned directly about their *own* experiences, some participants feel uncomfortable, or even unwilling, to

discuss such topics. Sensitive topics that have been explored utilising qualitative SC include orgasmic “absence” (Frith 2013) and sex offending (Gavin 2005).

3. ***SC offers robust and easy-to-implement comparative design options:*** This feature of SC can be useful to explore differences between different groups of participants or between different versions of the same story and how they are made sense of. Kitzinger and Powell’s (1995) ground-breaking study used a comparative design with unfaithful male and female partners in the story stem, and male and female respondents. Critical psychologists Ginny Braun and Victoria Clarke (2013) similarly used two versions of a story to explore people’s perceptions of trans-parenting. The story stem described a parent telling their children that they are uncomfortable living within their assigned gender and want to start the process of “changing sex.” Roughly half of the participants completed a male parent (Brian) version and half an otherwise identical female parent (Mary) version. Having two versions enabled the researchers to compare the responses both according to the gender of the parent character and the gender of the participant. This was important because mothers and fathers tend to be perceived very differently in the wider culture, and women tend to be more tolerant of gender diversity and nonconformity than men (Braun and Clarke 2013).
4. ***SC offers scope for methodological innovation:*** Qualitative researchers have only recently begun to fully explore the possibilities that SC offers. For example, critical psychologists Nikki Hayfield and Matthew Wood (2014) recently piloted a SC using visual methodologies (Frith et al. 2005) in their research on perceptions of appearance and sexuality. The stem described a dating scenario; once they had completed their stories, participants were directed to the website *Bitstrips* to create a cartoon image of the main character. A preliminary analysis of the images indicated that participants recognized the existence of lesbian and gay appearance norms, in a way which was not necessarily *as* apparent in their written responses. Hence, visual data may provide an anchor for, or “bring to life,” textual responses and can also be analyzed in their own right. This allows the potential for different understandings of, insights into, and interpretations of the findings (Frith et al. 2005).
5. ***SC is useful for researching social categories:*** The listed advantages of SC as a method – including the ease of implementing comparative designs – means that it fits well with research focused on understanding the operation of social categories such as gender, race/ethnicity, or sexuality. It enables researchers to explore any divergences in how different social groups make sense of a scenario, *and* whether participants respond differently to variations in, for example, the story character’s gender or sexuality.
6. ***SC methods have the advantage of being economical in terms of time and resources:*** In a context of reduced support for social sciences research, it can be an advantage that SC is a thrifty method! Being economical to use also makes SC eminently suited for student research projects. Hard copy stories, for instance, can be handed out to a large group of people and the completed stories returned in 30 minutes or so; online stories can be distributed (and then downloaded) with a few mouse clicks.

Table 1 Examples of existing story completion research

Topic area	Research question/focus	Theoretical framework
Internet infidelity	What are the perceived impacts of cyber-cheating on offline relationships? (Whitty 2005)	Essentialist (perceptions)
Sexual aggression	How do women perceive their vulnerability to sexual aggression in (heterosexual) dating contexts? (Livingston and Testa 2000)	
Infidelity	How do women and men represent unfaithful heterosexual relationships? (Kitzinger and Powell 1995)	Essentialist and constructionist
Sex offending	What cultural narratives do people draw on in stories about child sex offenders? (Gavin 2005)	Constructionist (discursive constructions)
Eating disorders	How are “anorexic” and “bulimic” young women discursively constructed in stories written by young people who do not self-identify as “eating disordered”? (Walsh and Malson 2010)	

4 Suitable Research Topics and Questions in SC Research

The flexibility of SC is one of its key advantages and, accordingly, it can be used to research a broad range of topics. SC is particularly suited to research exploring people’s perceptions and understandings and broader social constructions around a topic. However, questions that focus on people’s *lived experiences* are not well suited to SC research, because this method does not gather stories about participants’ *own* experiences. When developing a research question(s), as in any qualitative project, it is important to ensure it is both focused on a specific topic, but also broad and open-ended – for instance, the research is guided by exploratory “what” or “how” type questions. For example, Kitzinger and Powell (1995, p. 345) aimed to “explore young men’s and women’s representations of ‘unfaithful’ heterosexual relationships,” and Frith (2013, p. 312) examined “how people account for and explain orgasmic absence during heterosex.” These questions are specific enough to guide the research and design, but open enough so that there is plenty of scope for fully exploring participants’ responses. It is also important to ensure that the type of question created “fits” with the chosen epistemological approach; “perception” questions tend to be used in essentialist research, whereas “construction” and “representation” questions are most often used in constructionist and critical research. Table 1 provides examples of existing SC studies that demonstrate this.

5 Stem and Study Design in Story Completion Research

The most important design consideration in SC research is the design of the story stem: the “start” of a story that participants are asked to complete. A careful balance needs to be struck between providing the participant with a *meaningful* story stem

and leaving enough ambiguity for tapping into their assumptions. Braun and Clarke (2013) suggest six considerations in story stem design:

1. ***Length of the story stem:*** How much of the beginning of the story will be written? There are no hard and fast rules here; it depends on the topic and participant group. If the story concerns something likely to be familiar to participants, less detail is necessary for the scenario to be meaningful to them. For a less familiar or more complex topic, such as one focused on the character's psychology, participants may need more detail to understand the scenario that is the focus of the stem. For instance, critical psychologist Irmgard Tischner's (2014) research on constructions of weight-loss used a slightly longer stem: "Thomas has decided that he needs to lose weight. Full of enthusiasm, and in order to prevent him from changing his mind, he is telling his friends in the pub about his plans." Although weight-loss is a familiar topic to most people, the main focus of the research was on social perceptions and interactions around weight-loss *intentions*; this necessitated the story stem including the protagonist's interaction with other people, i. e., him telling his friends about his plans.
2. ***Authentic and engaging scenarios and characters:*** Unless the story, its protagonists, and the context resonate with the study participants, it is unlikely they will write a useful story. The stem should engage participants and be easy for them to relate to. Using names and scenarios that sound authentic and believable will help participants imagine or "see" the characters and the scenario, and thus to write a rich and complex story. These details can also cue (potentially not deliberately) certain cultural norms; for example, names may provide cues about ethnicity, class, or religion, which may then shape the stories told.
3. ***Amount of detail:*** The most difficult design decisions revolve around the issue of detail in the story stem. Too much detail and direction will potentially limit the variation and richness of the data; not enough could mean the participants will not know "where to take" the story, resulting in data that do not address the research question. Researchers need to design a story stem that stimulates a range of complex and rich stories – otherwise the analysis will not have much to say! To achieve this, give the participants adequate directions by giving them a context or background to the story, and some detail about the characters, and what the topic of the story should be about. At the same time, it is important to avoid overly constraining their responses, by describing the background and characters in too much detail. Participants need to know what their story should be about, but do not give them a suggested plot or ending. Thus, for a study exploring understandings of *motivations* for exercise, for instance, a very open story stem like "Toby decides to become more physically active. . . What happens next?" may take the stories in too many, and possibly undesired, directions, and not focus on Toby's motivations. On the other hand, giving participants a particular motivation in the story stem (e.g., "Toby wants to develop a six-pack to attract a boyfriend. . .") is likely to result in a lack of diversity in the data. A better stem for this topic could be "As Toby wipes the sweat off his face and tries to catch his breath, he wonders why he ever thought starting to exercise was a good idea."

4. ***Use of deliberate ambiguity:*** SC is particularly useful for the exploration of underlying, taken-for-granted assumptions around a topic – for example, the heteronormative assumption that a couple consists of a man and a woman. This can often be achieved by leaving certain elements of the story ambiguous, such as some demographic characteristics of the protagonists (e.g., class, sex, race, sexuality, age). However, if the research question necessitates focusing participants' attention on a particular detail of the story, this should not be left ambiguous.
5. ***First or third person:*** One design consideration concerns the standpoint the researchers want participants to take. Is it important participants step into the shoes of, and empathize with, one particular protagonist? Or is it better if they assume the position of an omniscient narrator? Although to date qualitative SC has involved mostly third person story stems, first person stems are possible (e.g., Livingston and Testa 2000). These can be useful if it is important for the participants to write from the perspective of a specific character. From a classical projective standpoint, first person SC is assumed to prompt more socially *desirable* responses (Rabin 1981). Therefore, if the researchers want to gain a *broader* range of stories, including socially undesirable responses, it is recommended to use a third person stem. However, as this approach is still new, the impact of participant perspective is also something that can be explored within research design!
6. ***A comparative design:*** A final design consideration is whether or not to use a comparative design. A comparative design allows exploration and comparison of assumptions made, or perceptions held, about certain social groups or scenarios. If this is a research aim, it is necessary to design versions of the story which reflect the specific differences of interest, and to allocate roughly equal numbers of participants to each of these. It is better not to have too many versions of a story in one study, and to avoid using overly complex designs, because qualitative research is primarily about understanding (potentially complex and dynamic) meaning, rather than compartmentalization – the latter is a specialty of quantitative research designs. Two to six covers the manageable spectrum for comparison for small and medium-sized projects, in terms of both participant recruitment and analysis. The other main way comparison can be included in the design involves different participant groups, and exploring the differences between the stories written by people who are, for instance, from different genders, sexualities, generations, or cultural or educational backgrounds. This requires the recruitment of sufficient numbers of participants from each demographic category concerned. For example, counseling psychologist Naomi Moller's (2014) research on perceptions of fat therapists included responses from 18 to 21 year-old undergraduate psychology university students and 16–18 year-old sixth formers. This design made it possible to consider the salience of counselor body weight for the whole group of young people, but also showed how small differences in age and educational experience impacted on the expression of fat stigma. Whereas the stories of both groups clearly reiterated anti-fat cultural narratives, the younger cohort were much more direct in their expression.

6 Completion Instructions for SC

After designing the story stem(s), the researchers need to write completion instructions for participants. In the *participant information sheet*, provide participants with some information about the nature of the task, and what they are expected to do, emphasizing the necessity of writing *a story*. Here is an example from Victoria Clarke's (2014) research on body hair:

You are invited to complete a story – this means that you read the opening sentences of a story and then write what happens next. There is no right or wrong way to complete the story, and you can be as creative as you like in completing the story! I am interested in the range of different stories that people tell. Don't spend too long thinking about what might happen next – just write about whatever first comes to mind. Because collecting detailed stories is important for my research, you are asked to WRITE A STORY THAT IS AT LEAST 10 LINES/200 WORDS LONG. Some details of the opening sentence of the story are deliberately vague; it's up to you to be creative and 'fill in the blanks'!

Then, ideally just before or after participants are presented with the story stem, provide specific instructions on how they should complete the story. Completion instructions can vary from the broad and open to the more prescriptive and directive. For example, Clarke (2014) instructed participants to simply “read and complete the following story.” Another common instruction is to ask participants to write “what happens next.” Nikki Hayfield and Matthew Wood's (2014) research on sexuality and appearance provides an example of a more prescriptive approach. Because they wanted participants to focus on the events before, during and after the female character's date, they instructed participants to write their story in three sections. Their story varied by character sexuality (bisexual, lesbian and heterosexual) – these are the instructions for the lesbian version:

Jess is a 21 year old lesbian woman. She has recently met someone, and they have arranged to go on a date.

- Please write about the run-up to the date and how she prepared for it. . .
- Please write about the date and how it went. . .
- Please write about what happened next. . .

(Please feel free to write as much as you like about the characters and as far into the future as you like).

Researchers may also want to provide participants with clear instructions on the length of story they wish them to write, or a time-expectation, to help ensure the stories generate rich, useful data. For example, instruct participants to spend a certain amount of time writing their story (e.g., “please spend at least 10 minutes”), or to write stories of a particular length (e.g., see Clarke's 2014, example above). Such instructions are particularly important for participant groups who are not necessarily highly motivated, such as individuals who take part in order to access particular benefits associated with participation (e.g., research participation for course credit within universities).

7 Asking Additional Questions in SC Research

Although one of the key features of SC is that it provides an indirect approach, some researchers have combined the use of a story stem with a small number of direct questions (in a way that combines some aspects of vignettes, a related data collection approach; see Gray et al. [in press](#)). For example, Naomi Moller's (2014) research on perceptions of fat therapists involved asking participants a direct question about the counsellor featured in the story stem: "What weight did you think the counsellor was?" The answers to this question allowed Moller to understand how the participants' defined "fat" – a variable construct – and provided a conceptual anchor for interpreting their stories.

Researchers should also consider whether it is important to ask participants demographic questions beyond the "standard" questions about age, sex/gender, race/ethnicity, sexuality, disability and social class (see Braun and Clarke [2013](#)). Such questions can provide a useful "baseline" for interpreting and contextualizing stories. For example, in her research on body hair, Victoria Clarke (2014) asked a series of questions about whether participants had currently or previously removed or trimmed body hair in particular areas and their reasons for doing so. Given that for women, but increasingly for men too, body hair removal is a dominant social norm (Braun et al. [2013](#); Terry and Braun [2013](#)), an overview of the participants' own body hair practices provides important information for contextualising the data.

8 Sampling in Story Completion Research

How many participants or stories is the "right" number? In existing SC research, there is a large variation in sample sizes – from 20 (Walsh and Malson [2010](#)) to 234 (Whitty [2005](#)) participants. Sample size depends on a number of factors, including: (a) the complexity of the design – more stories generally require more participants to be able to say something meaningful about each version, especially if researchers intend to make comparisons; (b) the richness of individual stories – richer stories mean fewer participants (note, however, that it may not be possible to predict in advance how rich the stories will be); and (c) the purposes of the research. For a small student project, with a single stem design, and no comparison between different participant groups, a sample size of around 20–40 participants is likely to provide data that are rich and detailed enough for a meaningful analysis. The more comparisons made, the bigger the overall sample will need to be. Braun and Clarke (2013) advise recruiting *at least* ten participants per story stem variation, but to publish the study, journal editors and reviewers may require higher participant numbers than that.

Of course, as with any research, recruiting enough participants can be a challenge, which is why many studies are carried out with a student population. Students, however, are a very specific population, and often not very diverse in terms of demographics. At the same time, students *are* used to discussing and describing ideas in writing, tend to be fairly literate, and thus will not struggle with the task of

writing a story (Kitzinger and Powell 1995); the same cannot be assumed for all other participant groups. Think carefully about the needs and expectations of the study participants – busy professionals, for example, may require very clear but short instructions.

Another sampling consideration is determining how many stories each participant will be asked to complete. When using a comparative design with multiple versions of the story stem, one option is to ask participants to complete one version, which is what Clarke (2014) did in her body hair research. Another approach is to get participants to complete more, or all, the versions. In psychologist Helen Gavin's (2005) research on the social construction of sex offenders, for instance, each participant was asked to complete *six* different versions of a story stem. She did so to explore how individual participants' narratives surrounding sex offenders varied when presented with different situations. Asking participants to complete more than one stem may reflect a more pragmatic concern to maximize the number of stories in the data-set. For example, Shah-Beckley and Clarke (2015) were able to halve the number of required participants by asking them to complete two versions of a story stem related to therapists and non-therapists' constructions of heterosex.

One concern when asking participants to respond to multiple story stems is that there may be order effects, which could have different impacts. Participants may write their longest story first, and the richness and quality of data may drop off. However, in Shah-Beckley and Clarke's study (2015), the opposite was true, with participants writing longer stories in response to the second stem. Randomizing order can reduce the risk of systematic impact across different stems. A second concern is whether, through more than one stem, the participant gets "cued in" to what the researcher is interested in, and starts to tell the "right" story. Whether or not this is a concern still needs to be determined, and whether/how it potentially impacts the research likely depends primarily on the specifics of each study.

9 Data Collection and Ethical Considerations in Story Completion Research

When it comes to actually collecting SC data, the key consideration is whether to conduct the study using "paper and pen" completion, or electronically either online using (free or subscription) survey software such as *Qualtrics* (www.qualtrics.com) or *SurveyMonkey* (www.surveymonkey.com), or by emailing the SC to participants as an attachment or in the body of an email (see ► Chaps. 76, "Web-Based Survey Methodology," ► 78, "Synchronous Text-Based Instant Messaging: Online Interviewing Tool," and ► 79, "Asynchronous Email Interviewing Method"). An advantage of hard copy completion is that researchers can hand the SC directly to participants (for example, if researchers recruit on university campuses or at specific events), and, providing they have ethical approval, offer participants a small "reward" (e.g., a chocolate bar) for returning their story. A downside of hardcopy is that researchers then need to manually type up participants' stories ready for analysis.

The key advantage of *electronic* data collection is that responses require little preparation for analysis – emailed stories will need to be cut and pasted and collated in a document; online responses can be downloaded into a document almost instantly (see ► [Chap. 79, “Asynchronous Email Interviewing Method”](#)). Furthermore, participants can complete the study at a time and place that suits them. However, online SC research that requires participants to have Internet access can limit who can take part; it is the least privileged members of society that tend to have limited or no Internet access (Hargittai 2010), and some groups (such as older participants) *may* be uncomfortable with, or find difficult to use, certain types of technology (Kurniawan 2008). Finally, another important consideration is achieving a good fit between the mode of data collection and the participant group. Researchers do not have to restrict themselves to one mode – it may be most appropriate to ask some participants to complete the study online and others on hard copy.

9.1 Piloting in SC Research

Given the open-ended and exploratory nature of SC research, piloting the stem and instructions to ensure they elicit relevant and useful data is vital (Braun and Clarke 2013). We have often made minor (but transformative) amendments to story stems or instructions following piloting. The nature of SC means that piloting is not generally an onerous task. It is recommended that researchers pilot the stem on the equivalent of 10–20% of the intended final sample; the precise number should be determined in relation to the diversity within the participant group: greater diversity = larger pilot sample. Piloting can be approached in one of two ways: (1) by treating early data collection as a pilot, and using participant responses to judge if the stem and instructions have been interpreted in the way(s) researchers intended; (2) by asking participants to both complete the study *and* comment on the clarity of the instructions and the study design, after completion. If researchers make no (or minimal) changes to the stem following piloting, the pilot data can be incorporated into final sample.

9.2 Ethics in SC Research

As a general rule, SC research raises fewer ethical concerns than research that involves direct interaction with participants and asking them about their personal lives; this is particularly the case for online SC studies that make it even easier for participants to be anonymous and reduce risk for both participants and researchers. However, participant comfort with the topic is still an important ethical consideration, particularly for sensitive topics, and standard accepted ethical practice still needs to be adhered to (e.g. American Psychological Association 2010; British Psychological Society 2009). Researchers should also follow the relevant ethical guidance of their institution and/or professional body (see ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)).

10 Analyzing Story Completion Data

To date, two methods have been used to analyze SC data – thematic analysis (TA) (e.g., Livingston and Testa 2000; Frith 2013; Clarke et al. 2015; see ► Chap. 48, “Thematic Analysis”) and discourse analysis (DA) (e.g. Walsh and Malson 2010; see ► Chap. 50, “Critical Discourse/Discourse Analysis”). Following Kitzinger and Powell, TA (Braun and Clarke 2006, 2012) is often slightly adapted from its usual use with self-report data. That is, rather than simply identifying patterns across the stories as a whole, researchers have identified patterns in specific elements of the story (both of these can be thought of as a variant of *horizontal* patterning, in the sense that the patterns intersect the stories). For example, SC research on perceptions of relational infidelity has identified patterns in how both the relationship between primary partners, and between the unfaithful partner and the “other” man/woman, is presented, how infidelity is accounted for, and how the responses to, and consequences of, infidelity are depicted (Kitzinger and Powell 1995; Whitty 2005). This means that SC researchers have identified particular questions they want to ask of the data – either in advance of the analysis, or after data familiarization – and used the techniques of TA to identify patterns in relation to these questions.

As noted above, Kitzinger and Powell (1995) demonstrated that both essentialist and constructionist readings of SC data are possible, and TA has been used to analyse SC data in both essentialist and constructionist ways. Pattern-based DA is also an ideal analytic approach for constructionist approaches to SC (Braun and Clarke 2013). For example, critical psychologists Eleanor Walsh and Helen Malson (2010) used poststructuralist DA (e.g., Wetherell et al. 2001) to interrogate some of the ways in which their participants made sense of anorexia and bulimia, and constituted the causes of, and recovery from, eating disorders. They explored how the participants constructed “dieting” as normal and healthy, for instance, and the ways in which recovery from eating disorder was framed in terms of a return to “normal” dieting rather than (say) a return to unrestricted eating or a lack of concern with body weight.

10.1 Story Maps

In addition to identifying *horizontal* patterning in the data, SC researchers have also examined *vertical* patterning – patterns in how stories unfold. One approach very useful for this type of “narrative” analysis is Braun and Clarke’s (2013) story mapping technique that involves distinguishing patterns in the key elements of a story’s progression (see also ► Chap. 64, “Creative Insight Method Through Arts-Based Research”). Braun and Clarke provide the example of a study exploring perceptions of a young woman “coming out” to her parents as non-heterosexual. The story map for this study identified patterns in: (1) the parent’s initial reactions to the coming out; (2) the development of the stories; and (3) the ending or resolution of the stories. After an initial expression of shock, the parents’ responses to their daughter coming out were categorized as either (broadly) positive or negative; the

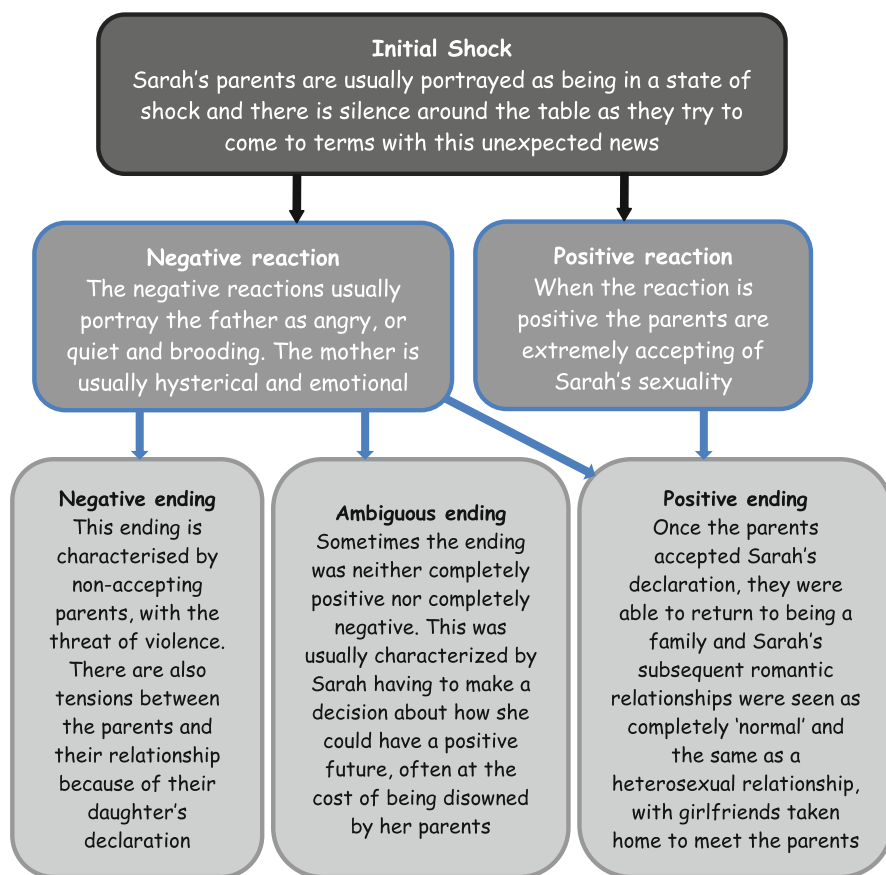


Fig. 1 An example of a story map (Braun and Clarke 2013)

negative reaction stories either ended positively, negatively or ambiguously, and the positive reaction stories always ended positively (see Fig. 1). Depending on the research question and approach, this story mapping technique can be a useful complement to a standard pattern-based analysis (e.g., TA), which helps the analysis to retain a sense of the storied nature of the data. This technique also lightly captures (Western) cultural conventions around story-telling (beginning, middle, end) and the dominance of particular genres (e.g., “happily ever after,” “triumph over adversity”), and forces the researcher to think about the ways these are part of data production using SC.

One analytic approach that has yet to be used to analyse SC data, but nonetheless seems particularly apt, is narrative analysis (e.g., Riessman 2007). Narrative techniques could be productively used to identify narrative types and genres, and the structures and styles of particular narrative types, thus extending and developing Braun and Clarke’s (2013) story mapping technique.

10.2 Frequency Counts

Researchers who do qualitative research within a qualitative paradigm do not generally recommend the use of frequency counts in the analysis of self-report data, because of the organic and participant-responsive nature of self-report data collection (Braun and Clarke 2013). However, frequency counts *are* often used in the analysis of SC data. For example, in their research on perceptions of infidelity, Kitzinger and Powell (1995) asked how many participants interpreted the female protagonist Claire “seeing someone else” as Claire being unfaithful – a full 10% rejected the implications of infidelity. When asking such concrete questions of the data (and when participants have been set an identical task), reporting numbers or percentages rather than using looser words such as “most” or “some” to capture patterning in the data is both appropriate and potentially analytically informative.

10.3 Analysis Approaches to Avoid

Certain analytic approaches are *not* suited to the analysis of SC data, including approaches such as interpretative phenomenological analysis (Smith et al. 2009) and forms of narrative analysis focused on understanding participants’ lived experiences (Riessman 2007). Because participants are not asked for their views directly, and are often asked to write stories about things they may have little or no personal experience of, it is unclear whether SC data tell us anything meaningful about participants’ lived experience. Without some big interpretative leaps, SC data would need to be combined with another data source to be suitable for use in research focused on lived experience. Grounded theory has similarly not been used to analyze SC data, and the focus on theory generation and the examination of the social processes and factors that shape particular phenomenon (Charmaz 2006) suggest that it is unlikely to be an appropriate method for analyzing SC data. Finally, approaches centred on the analysis of language practice – such as conversation analysis (e.g., Schegloff 2007) and discursive psychology (e.g., Wiggins and Potter 2010) – are not well suited to SC data. These approaches typically focus on “talk-in-interaction”; the “what” and “how” of “real” talk – both everyday “real” talk and that produced in institutional contexts such as courtrooms or consulting rooms – which is rather different from written, storied data.

11 Conclusion and Future Directions

It is hoped that this chapter conveys the enthusiasm of a group of committed SC researchers. In our view, SC is a method for producing data that provide an exciting, viable, and very accessible, alternative to self-report methods of data collection. SC allows participants control and creativity, and the resulting data can be fun, rich and complex. SC also offers researchers new ways to generate data that provide compelling insights into their chosen topics. This said, the method is still relatively

unknown, with as yet a small but growing body of literature evidencing its use and potential. This leaves some questions still to be explored in future research, such as:

1. ***What is distinct about SC?*** As noted, there are overlaps between SC and vignette research; there are also overlaps between SC and diary research (see ► Chap. 83, “Solicited Diary Methods”) – another often written solicited account. Points of overlap and of difference between these forms of data collection could further be delineated.
2. ***What sample size is best?*** To date, studies have used quite varied sample sizes. Ideal sample sizes, and whether or not a higher N offers more convincing and useful data/results, remain important questions to keep exploring.
3. ***Does SC work well with a wide range of sample populations?*** So far, SC has predominantly been used with UG students, who are educated, literate, and used to putting thought into textual form. How well SC works with different populations thus remains an important question. For instance, does it work well for less educated populations? How might it work in populations with different story-telling traditions? Could it also work effectively as an oral method, such as in clinical contexts, or with children?
4. ***What are the factors that explain why SC does not always work?*** Sometimes, SC data can, for instance, be flat, restricted in scope, or very brief. Some of the potential causes have been discussed, such as over-specifying the stem; another possibility to consider is whether even a hypothetical scenario may prove threatening to participants in some way, thereby restricting the data. For instance, in Shah-Beckley and Clarke’s (2015) study, potential concerns about their own professional competence may have been evoked in the respondents, leading to “flat” data. Are there other consistent aspects to consider in designing effective stems?
5. ***What can and should be done with story “refusal”?*** Story refusal is when the participant either effectively ignores the stem topic, or offers up a humorous and/or fantastical story – such as accounts of a (hairy) yeti in our hair removal research, or of a monster/therapist eating the storyteller/client in our research on perceptions of fat therapists. These stories exemplify the creative potential that participants have with SC research – and can provide great pleasure to read as a researcher – and in some cases, the discursive or thematic aspects may resonate with the more conventional stories provided (e.g. that it is monstrous to be hairy/fat). But the theory of what such data mean still requires some thought.
6. ***Finally, what is the potential of other analytic approaches to SC data?*** What is the cost and the benefit of not focusing on the *storied* aspect of this approach? What potential is there in using narrative analysis to provide quite different insights to those offered by TA and DA?

These questions are important ones for the development of SC, but already, the evidence indicates that SC offers a valuable alternative to existing methods of qualitative data collection. The existence of questions offers researchers the opportunity to explore and innovate. Have fun with it!

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Section III

Doing Cross-Cultural Research in Health Social Sciences



Doing Cross-Cultural Research: An Introduction

86

Pranee Liamputtong

Contents

1	Introduction	1499
2	About the Section	1500
	References	1505

Keywords

Cross-cultural research · Multicultural societies · Indigenous peoples ·
Marginalized people · Ethical issues · Methodological issues · Moral challenges

1 Introduction

Globally, cross-cultural research has become increasingly essential. In multicultural societies like the UK, USA, Canada, New Zealand, and Australia, there has been an increasing number of people from different cultural and linguistic backgrounds. Meeting the needs of our multicultural society requires a cultural awareness of the diversity and commonality of people's beliefs and practices. It is argued that this can be obtained by research, particularly with culturally sensitive approach. Therefore, cross-cultural research is a valuable tool for advancing an awareness of belief systems and practices among diverse cultural groups. The need for culturally competent research is now urgent in view of current social and health policies in many developed countries and their attempts to address the needs of multiethnic populations.

The presence of indigenous populations in countries such as Canada, the USA, New Zealand, and Australia has a great ramification for social science researchers. These indigenous people have been colonized, damaged, and become marginalized

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1499

in their own native lands. Due to a concern about reducing inequalities between the indigenous people and the “white” populations, there have been attempts to include these marginalized people in the research arenas. Again, this has barely been discussed in the literature. In this Handbook, I will include some examples on researching with the indigenous population.

Conducting research with marginalized people in cross-cultural settings is rife with methodological, ethical, and moral challenges (Liamputtong 2010, 2013). Researchers are challenged by a vast array of issues for carrying out their research with people in cross-cultural arenas. In this section, I bring together salient issues for the conduct of culturally appropriate research. The task of undertaking cross-cultural research can present researchers with unique opportunities, but also provide dilemmas. The section will give some thought-provoking points so that our research may proceed relatively well and yet remains ethical in our approach. To make the section more comprehensive, I am covering both methodology and procedural sensibilities (including ethics) in this Handbook.

2 About the Section

The section on doing cross-cultural research in health social sciences comprises four parts. Section 1 focuses on methodologies and research processes in cross-cultural research. In Section 2, language issues are included. Section 3 embraces chapters that discuss culturally sensitive research methods and processes, and the last part dedicates to ethics in cross-cultural research in health social sciences.

In ► [Chap. 87, “Kaupapa Māori Health Research,”](#) Fiona Cram writes about ► [“Kaupapa Māori Health Research.”](#) She argues that Kaupapa Māori is “literally a Māori way” which has been theorized in response to the colonization in Aotearoa New Zealand. Māori (Indigenous peoples) have been marginalized in their own lands, as evidenced by widespread social disparities. Kaupapa Māori health research, according to Cram, “promotes a structural analysis of Māori health disparities that moves the discourse away from victim-blaming and personal deficits to more fully understanding people’s lives and the systemic determinants of their health and wellness.” In this chapter, Cram uses Kaupapa Māori health research to illustrate the nature of the research paradigm as well as discusses what it means for Māori researchers undertaking Māori health research.

Denise Wilson, in ► [Chap. 88, “Culturally Safe Research with Vulnerable Populations \(Māori\),”](#) writes about culturally safe research with vulnerable populations but particularly with Māori. Wilson contends that often, vulnerable populations are subjected to some forms of social marginalization. Researchers’ decisions and the research processes they employ can further increase the risk of vulnerability and marginalization among these people. She contends that “creating culturally responsive and safe spaces and research contexts with Maori, and others vulnerable within research settings, are needed to minimize participants’ vulnerability and marginalization and counter unhelpful constructions about them.” In this chapter, she offers some strategies

that aim at minimizing the vulnerability of individuals participating in research. She provides a framework based on the concepts of partnership, participations, protection, and power to help researchers' cultural responsiveness in order to get the research story right, and importantly, to improve the utility of their research.

In ► [Chap. 89, "Using an Indigenist Framework for Decolonizing Health Promotion Research,"](#) Karen McPhail-Bell, Alison Nelson, Ian Lacey, Bronwyn Fredericks, Chelsea Bond, Mark Brough write an interesting chapter on using an Indigenist framework for decolonizing health promotion research. The chapter explores the way the principles of Indigenist research informed the study, as a critical reflection of the methodology's achievement of a decolonizing research agenda. The flow of Maiwah (the Brisbane River in Australia) is used as a metaphor for the diverse authorship. The flow of Maiwah signifies the dialogical approach of the research; what Linda Smith (2005) refers to as a "tricky ground." The flow of Maiwah also shows us the possibilities of research where researcher and participants co-create new knowledge in support of their own agendas.

In ► [Chap. 90, "Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,"](#) the Dubbo Aboriginal Research Team (Craig Johnson, Monica Johnson, Bernie Kemp, Valerie Smith, Emma Webster and Billie Townsend) write about engaging Aboriginal people in research. They contend that much research in Australia has been done on Aboriginal people, but Aboriginal people themselves have received little benefit from it. This has added to distrust between Aboriginal and non-Aboriginal people over many years. In this chapter, they share aspects of their research that value Aboriginal people. The authors also discuss tensions which occur between the "scientific way" and the "culturally appropriate way" and offer how they resolve this.

Chijioke Obasi discusses issues of identity in research in ► [Chap. 91, "Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women."](#) She examines the impacts of the identity of the researcher, participants, and the various identity interchanges that take place in her research with five culturally Deaf (white) women and 25 Black (hearing) women. The chapter offers a reflexive account of the research; however, it is done in a way that centralizes the perspectives of the participants. In this chapter, Obsi raises a number of important questions, for example, should researchers seek out participant perspectives on the insider/outsider debates in research? and in what ways does the identity interchange between the researcher and the researched have an impact on the research process?

"Researcher Positionality in Sensitive Qualitative Research" is about researcher positionality in cross-cultural and sensitive research and is written by Narendar Manohar, Pranee Liamputtong, Sameer Bhole, and Amit Arora (► [Chap. 92, "Researcher Positionality in Cross-Cultural and Sensitive Research"](#)). The authors argue that the status of the insider and outsider is an important concept for cross-cultural and sensitive research and in recent years, the concept of placement of the researcher has received much attention. The way research participants "place" the researchers, and vice versa, is crucial for the success of any research. In this chapter, the authors introduce the concept of researcher positionality, examine the debates on researcher positionality in cross-cultural and sensitive research, and

discuss “placing” issues including gender, age, culture and ethnicity, social class, and shared experiences.

In Section 2, in the language issues in cross-cultural research section, three chapters are included. In ► [Chap. 93, “Considerations About Translation: Strategies About Frontiers,”](#) considerations about translation are discussed by Lía Rodríguez de la Vega. She argues that the translation of any text entails different methodological issues that range from linguistic treatment, grammatical issues of the languages considered, lexical issues and how to approach them, space and time considerations in a given textual construction, implied ethical questions, and so on. This chapter draws on a bibliographic review and the experiences of researchers who translate or have translated different types of texts in a nonprofessional manner.

In ► [Chap. 94, “Finding Meaning: A Cross-Language Mixed-Methods Research Strategy,”](#) Catrina A. Mackenzie writes about finding meaning in a cross-language mixed-methods research strategy. She argues that the literature that devoted to methodological issues arising from working through an interpreter is sparse. Interpreters are crucial to the research process when a foreign researcher conducts research with an indigenous culture and when the researcher is not fluent in the local language. In this chapter, the author discusses an experientially developed cross-language research strategy.

Caroline Elizabeth Fryer, in ► [Chap. 95, “An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups,”](#) writes about an approach to conducting cross-language qualitative research with people from multiple language groups. She writes that a lack of shared preferred language between researcher and participant creates complexity and additional challenges in the research process. This is particular so when participants are from multiple language groups. In this chapter, Fryer introduces a research approach and methods which have been successfully used to conduct in-depth interviews with people from multiple language groups in a constructivist grounded theory study. She offers key strategies for conducting culturally competent and rigorous research at modest cost. She contends that this approach can enable health researchers to take “able to speak English” out of the inclusion criteria of studies and hence those who have limited English proficiency can be more included in health research.

► [Chapter 96, “The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research,”](#) written by Sara Stevano and Kevin Deane, is on the role of research assistants in cross-cultural social science research. As we have seen, cross-cultural research often involves working with research assistants who assist with the data collection activities. Their participation in the research project has ramifications for the quality of the research. This chapter discusses a set of key practical decisions that researchers should make when planning their research fieldwork. The authors also explore how the triangular power dynamics between research participants, research assistants, and researchers impact on the research process and outcomes.

The next section is on culturally sensitive research methods in cross-cultural research and there are nine chapters. In ► [Chap. 97, “Indigenous Statistics,”](#) Tahu Kukutai and Maggie Walter discuss Indigenous Statistics. The authors contend that in Anglo-colonizing nation states such as Canada, Australia, Aotearoa New Zealand,

and the United States (CANZUS), statistics about Indigenous peoples are a common feature. In this chapter, they “contrast these statistics with those from statistical research using processes and practices that are shaped by Indigenous methodologies.” Indigenous methodologies are characterized by their “prioritization of Indigenous methods, protocols, values, and epistemologies.” They conclude the chapter with two examples of what Indigenous quantitative methodologies look like in practice from Aotearoa NZ and Australia.

► [Chapter 98, “A Culturally Competent Approach to Suicide Research with Aboriginal and Torres Strait Islander Peoples”](#) is about a culturally competent approach to suicide research with Aboriginal and Torres Strait Islander Peoples and is written by Monika Ferguson, Amy Baker, and Nicholas Procter. Suicide has profound, and ongoing, impacts for Aboriginal and Torres Strait Islander Peoples and has been identified as an area requiring further research. In this chapter, the authors outline a culturally competent approach for conducting social and emotional well-being research, from the perspective of non-Aboriginal researchers. They outline sensitivities associated with conducting research as non-Aboriginal researchers and then introduce important ethical principles, which can be used to guide culturally competent practice throughout the research journey. Specific methodological approaches with an emphasis on those that are participatory in nature are also outlined.

In ► [Chap. 99, “Visual Methods in Research with Migrant and Refugee Children and Young People,”](#) visual methods in research with migrant and refugee children and young people were presented by Marta Moskal. In this chapter, Moskal examines how visual methods can be utilized in understanding and interpreting migrant and refugee children’s worlds. She argues that visual methods can secure the engagement and reflexivity among children who may not feel comfortable with a traditional interview, focus group, or survey methods. Several visual methods including drawing, maps, photographs, and videos are discussed in the chapter.

Oana Marcu, in ► [Chap. 100, “Participatory and Visual Research with Roma Youth,”](#) writes about participatory and visual research with Roma youth. Oana discusses methods, tools, and strategies which can be used in peer-research with young people belonging to minorities, from migrant backgrounds or marginalized ethnic groups. In this chapter, research strategies including the participatory design process and the selection of specific levels of participation in all stages are discussed. Visual and participatory methods are illustrated with examples from two research projects: the representation of drugs and the migratory experience from a gendered perspective.

In ► [Chap. 101, “Drawing Method and Infant Feeding Practices Among Refugee Women,”](#) the drawing method and infant feeding practices among refugee women is presented by June Joseph, Pranee Liamputtong, and Wendy Brodribb. This chapter adopts the postmodern methodological framework to unravel the multiple truths that drive the perceptions and perspectives of infant feeding among mothers from refugee backgrounds (Myanmarese and Vietnamese) in Brisbane. Since the research trend of gaining visual access to the lives of mothers from refugee backgrounds is new, the authors also outline some tips and tricks that steered their initially rocky data collection journey. The chapter illustrates ways in which women from refugee backgrounds conceptualize motherhood and infant feeding. The authors also

delineate the usefulness of using drawing as a research method for researchers who work with refugee women and/or in a similar research domain.

In ► [Chap. 102, "Understanding Refugee Children's Perceptions of Their Well-Being in Australia Using Computer-Assisted Interviews,"](#) Jeanette A. Lawrence, Ida Kaplan and Agnes E. Dodds write about understanding refugee children's perceptions of their well-being using computer-assisted interviews. They suggest that children from refugee backgrounds have the ability and right to contribute to research knowledge. However, they need methods that enact respect and are theoretically appropriate for them. Two computer-assisted interviews (CAIs) were developed as research tools in their research with refugee children. The usefulness of the methodology is discussed in relation to the need to understand the perspectives of refugee children and other children about their well-being.

Norma Romm, in ► [Chap. 103, "Conducting Focus Groups in Terms of an Appreciation of Indigenous Ways of Knowing,"](#) writes about conducting focus groups in terms of an appreciation of Indigenous ways of knowing. In this chapter, Romm offers deliberations around the facilitation of focus groups in a manner which embraces Indigenous ways of knowing. Indigenous knowing, in this chapter, is "defined as linked to processes of people collectively constructing their understandings by experiencing their social being in relation to others." The chapter illustrates how the conduct of focus groups can be geared towards this epistemology.

► [Chapter 104, "Visual Depictions of Refugee Camps: \(De\)Constructing Notions of Refugee-ness?"](#) is about visual depictions of refugee camps which can deconstruct notions of refugee-ness written by Caroline Lenette. The author argues that visual representations of asylum seekers and refugees can have a marked impact on how these individuals are perceived in politically stable contexts, especially in western nations. Using refugee camps as the example, the author applies the framework of "humanitarian sentimentalism" which describes four typifications (or tropes) associated with images of humanitarian crises (Personification, Massification, Care, and Rescue) to visual depictions of refugee camps. The author contends that visual methodologies can provide a rich dimension to critical discussions on complex and multifaceted issues.

Jayne Pitard writes about autoethnography as a phenomenological tool that connects the personal to the cultural in ► [Chap. 105, "Autoethnography as a Phenomenological Tool: Connecting the Personal to the Cultural."](#) Autoethnography, Pitard writes "retrospectively and selectively writes about experiences that have their basis in, or are made possible by, being part of a culture and/or owning a specific cultural identity." In researching her role as the teacher of a group of vocational education professionals from Timor-Leste, she conducted a phenomenological study using autoethnography to portray the existential shifts in her cultural understanding. I also utilized vignettes to firstly place her within the social context and then to explore her positionality as a researcher. In this chapter, the author presents the framework that others can adopt in a cross-cultural setting.

The last section is on ethical issues in cross-cultural research and comprises three chapters. In ► [Chap. 106, "Ethics and Research with Indigenous Peoples,"](#) Noreen Willow writes about ethical health research involving Indigenous peoples. Willow contends that states and academic institutions have an obligation to support ethical

research with Indigenous peoples which would result in the elimination of health disparities among Indigenous peoples and others. Health research that respects Indigenous self-determination, and is safe, ethical, and useful for participants, necessitates increased capacity among Indigenous and non-Indigenous peoples alike. She argues that non-Indigenous researchers need appropriate ethical guidelines to follow and training opportunities that offer guidance on Indigenous ways of knowing, the social determinants of health, strength-based research approaches, community-based participatory research, and how to engage in culturally appropriate ways with Indigenous peoples.

Conducting ethical research with people from asylum seeker and refugee backgrounds is written by Anna Ziersch, Clemence Due, Kathy Arthurson, and Nicole Loehr in ► [Chap. 107, “Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds.”](#) In this chapter, the authors outline issues that need to be considered when working on health and other research with people with asylum seeker or refugee backgrounds in countries of resettlement. The chapter not only highlights the utility of a Social Determinants of Health framework, but also outlines the importance of ethical research which balances the considerations of formal ethics committees with the need for the voices of the most vulnerable people within this population to be heard. The chapter also offers some appropriate methodologies, including emerging and innovative research methods such as visual scales, photovoice, photolanguage, and digital storytelling, and discusses the ways in which these data collection methods contribute to high quality quantitative and qualitative data. In the last section of the chapter, the authors cover the challenges of working cross-culturally and the need to make sure that research is “culturally appropriate, consultative and meaningful.”

In ► [Chap. 108, “Ethical Issues in Cultural Research on Human Development,”](#) the last chapter in this section, ethical issues in cultural research on human development were discussed by Namrata Goyal, Matthew Wice, and Joan G. Miller (► [Chap. 108, “Ethical Issues in Cultural Research on Human Development”](#)). The authors argue for the importance of attending to culture in all phases of the research process. They also highlight ways that promote the ethical sensitivity of cultural research which enhances its explanatory force. They address ethical aspects of study design and data collection and point out ways that harm, coercion, and invasion of privacy may result from inadequate attention to cultural meanings and practices. Importantly, they discuss the impact of drawing unsound or stereotypical conclusions about culture and human development. They conclude their chapter by outlining ways in which culturally sensitive research can enhance both ethics and research quality.

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Kaupapa Māori Health Research

87

Fiona Cram

Contents

1	Introduction	1508
2	A Kaupapa Māori Research Paradigm	1511
2.1	Ontology: The Nature of Reality	1512
2.2	Epistemology: Relationship between the Knower and What would be Known	1514
2.3	Methodology: Appropriate Approaches to Systemic Inquiry	1515
2.4	Axiology: Nature of Ethics	1516
3	Conclusion and Future Directions	1520
	References	1522

Abstract

Kaupapa Māori is literally a Māori way. It is a response to the colonization in Aotearoa New Zealand that has seen Māori (Indigenous peoples) marginalized in our own lands, as evidenced by widespread health, education, socioeconomic, and other Māori-non-Māori disparities. What began in the late 1980s as Kaupapa Māori research within Māori education has spread to other disciplines, including Māori health. Kaupapa Māori health research promotes a structural analysis of Māori health disparities that moves the discourse away from victim-blaming and personal deficits to more fully understanding people's lives and the systemic determinants of their health and wellness. Describing this work as occurring within a Kaupapa Māori inquiry paradigm enables the exploration of its axiological (i.e., ethical), ontological (i.e., theory about the nature of reality), epistemological (i.e., theory of knowledge), and methodological (i.e., theory about how to find out things) assumptions. Kaupapa Māori health research is called upon to illustrate the nature of the paradigm as well as what it means practically for Māori researchers undertaking Māori health research. As part of transdisciplinary

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1507

research teams with Māori colleagues, Pākehā (non-Māori) researchers also have important roles to play in this research. The mission of Kaupapa Māori health research is ensuring that Māori health research informs an agenda of Māori being Māori, being fully human, and living in health and prosperity.

Keywords

Kaupapa Māori · Māori · Indigenous · Paradigm · Decolonization · Collaboration · New Zealand

1 Introduction

Colonized peoples have been compelled to define what it means to be human because there is a deep understanding of what it has meant to be considered not fully human, to be savage. (Smith 2012, p. 28)

Camara Jones (2000), a public health practitioner, tells a story about flower seeds growing in different types of flower boxes. Red flower seeds are planted in a flower box that has rich soil, full of nutrients. Pink flower seeds are planted in a flower box that has poor soil, full of clay and rocks. The red flower seeds flourish in their soil: they germinate, grow, and bloom. The pink flower seeds do not fare so well: few germinate, they grow spindly, and the blooms are few and far between. A person looking at just the mature plants might easily come to the conclusion that the red flower seeds are much better than the pink flower seeds. However, an examination of the soil will soon show them that something else has affected the “success” of the seeds. Jones uses the soil as a metaphor for understanding racism, that is, “behavior that stems from a belief that people can be differentiated mainly or entirely on the basis of their ancestral lineage” (Cochrane 1991, p. 127). This chapter is akin to the story of the flower seeds, with a slight but important twist. As a metaphor for colonization, this story begins in a previous era, when the pink flower seeds were sown in soil that nurtured them and they too thrived. The inquiry then becomes about how these flower seeds – Indigenous peoples – were exiled from the best soil or land and found themselves in marginal places that did not nourish them. And how the red flower seeds – colonists – came into possession of the best soil and what this has meant for the flourishing of all seeds.

The process of colonization depends upon the dehumanization of Indigenous peoples (Smith 2012). In other words, the belief that Indigenous peoples do not have human rights is foundational to the transfer of Indigenous resources and territories out of their hands and into the hands of newcomers. Through colonization, Indigenous peoples are driven to a low point and colonizers rise on a wave of artificial prestige. It should not be surprising, therefore, that the health and well-being of Indigenous peoples suffers under the burden of colonization. Even though Aotearoa New Zealand was one of the last places where the British Crown made a treaty with Indigenous peoples, with the 1840 Treaty of Waitangi, and the impacts of

colonization upon Māori (Indigenous peoples of Aotearoa New Zealand) were foreseen, they were not forestalled (Orange 1987; Walker 2004).

The relatively short history of the colonization of Aotearoa me te Waipounamu (the Māori names for these lands, shortened here as Aotearoa) saw Māori very quickly go from considering themselves ordinary (Orange 1987; Salmond 1991) to being seen by the British newcomers as different and deficient compared to their White ethnocentric norms. This helped justify the redistribution of Māori land and resources to the newcomers, with the outcome that Māori were pushed to the margins of a renamed, colonized New Zealand (Walker 2004). This marginalization and the vulnerability of Māori children and whānau (families) is reflected in lower life expectancy (some 7.3 years lower for Māori compared to the NZ European population) and the segregation of two-thirds of Māori households within the most deprived neighborhoods (Ministry of Health 2015).

The role of research in the colonization of Māori is not often considered. Rather descriptions tend to focus on broken treaty promises, land wars, and subsequent land confiscations, disease, and overwhelming settler numbers. However, in his comparison of political and scientific colonialism, Nobles (1991) places research alongside these other forces as central to colonization. He describes scientists as believing they have the right to access any knowledge, and then export this raw material from communities so that it might be “processed” into books, patents, new drugs, and wealth. The result is that a people’s knowledge is often relocated outside their community or tribal boundaries and beyond their control. This description can be applied to how non-Indigenous researchers journeyed until very recently within Māori communities.

Some of the first non-Indigenous scientists who wrote about Māori were aboard the Endeavor when it visited Aotearoa in 1769–1770. Captain James Cook wrote: “The Natives of this Country are strong, raw boned, and well-made” (Beaglehole 1968, p. 278), while Joseph Banks (1896, p. 240) reported: “A further proof, and not a weak one, of the sound health that these people enjoy, may be taken from the number of old people that we saw.” Banks felt that the health of Māori was due to a sound health philosophy system rather than good luck. He wrote: “Such health drawn from so sound principles must make physicians almost useless” (Salmond 1991, p. 279). In Jones’ (2000) gardener’s tale speak, the soil for Māori at this pre-colonial time was rich and nurturing.

When Darwin visited some 60 years later in 1835, he described Māori as “...fearsome people...a more warlike race of inhabitants could be found in no part of the world...[whose] shifty looks betrayed a fierce cunning, and tattooed face revealed a base nature” (Desmond and Moore 1991, p. 174–5). At this time, missionaries in this country held views that denied the humanity of Māori, setting the scene for the subordination of Māori and the theft of Māori land and resources.

Māori were, according to Henry Williams, ‘governed by the Prince of Darkness’. Robert Maunsell thought Māori songs were ‘filthy and debasing’. Even the Catholic Bishop Pompallier thought of the Māori as ‘infidel New Zealanders’. (Walker 1994, p. 102)

From the 1830s, Māori health was declining in response to contact with newcomers. At the beginning of the nineteenth century, the Māori population ranged from 200,000 to half a million (Durie 1998). By 1856, when a census recorded 56,049 Māori and 59,413 Pākehā (non-Māori), politician Isaac Featherston speculated, “[t]he Maoris are dying out, and nothing can save them. Our plain duty as good, compassionate colonists is to smooth down their dying pillow” (Dow 1999, p. 48). By 1887, the Pākehā newcomer population was more than 700,000 while the Māori population had further declined to just under 40,000 (Pool 1991). While the Māori population started to recover in 1890s, the imposition of colonial health, economic, education, and land policies continued to marginalize Māori. The rapid decline in Māori health has been attributed to land loss that led to the loss of an economic base and a source of identity, the undermining of cultural knowledge and connectedness (Kunitz 1994), and the demoralization of Māori (Orange 1987). In places where land seizure was most rapid, for example, the ratio of Māori children to women was lowest (indicating high child mortality) (Pool 1991; Kunitz 1994). At the heart of Māori land loss, in turn, are the broken promises of the 1840 Treaty of Waitangi that guaranteed Māori continued possession of their resources, rangatiratanga (sovereignty), and citizenship rights (Orange 1987).

Fast forward to the latter part of the twentieth century, when Māori were increasingly migrating to urban centers in the 1950s and 1960s, the colonial agenda intensified for all New Zealanders to mix and integrate to become one culture – largely by turning Māori into British New Zealanders (Walker 2004). Pākehā researchers largely undertook research on Māori during this time. Te Awekotuku (1991, p. 12) describes this as a continuation of “. . . many decades – even centuries – of thoughtless, exploitative, mercenary academic objectification.” In a similar vein, Linda Smith (1992, p. 7) calls these researchers “willing bedfellows of assimilationist, victim-blaming policies.” These researchers lacked an understanding that the knowledge system and worldview of newcomers to this land was being privileged (Smith 2012a). They also failed to recognize that research is about power, and power commands the (re)distribution of resources (Te Awekotuku 1991).

When Indigenous attendees at a 1992 meeting held by the Royal Commission on Aboriginal Peoples in Canada talked about research as a colonizing tool, they described Aboriginal communities as having “been researched to death” (Brant Castellano 2004, p. 98). While they may have been meaning some metaphorical death, they could just as easily have been referring to research being implicated in the deaths of Aboriginal people and of researchers failing to address this in their various studies within First Nations communities. The reply of an Aboriginal elder to this talk was that “[i]f we have been researched to death, maybe it’s time we started researching ourselves back to life” (Brant Castellano 2004, p. 98). For Māori, this life has to be a fully human life, a Māori life – as emphasized by Linda Smith (2012) in this chapter’s opening quote.

As an intervention strategy, Kaupapa Māori rests upon the principles that inform this life (see below, Ontology). A Kaupapa Māori inquiry paradigm speaks to how research can support this decolonization agenda. Here this paradigm is described with a particular focus on Māori health that, in turn, requires an expansion of

understandings of health to reflect Māori culture, traditions, and beliefs (see below, Epistemology). The writing of other Indigenous peoples is included to support and expand on points made. The result is not a checklist or a how-to guide. Rather, this chapter is a request for health research that advocates for a world that includes a Māori world. This re-inclusion of Māori as ordinary, as normal, is a Treaty of Waitangi obligation as well as a cultural survival necessity.

2 A Kaupapa Māori Research Paradigm

When seeking ways to eliminate widespread health, education, socioeconomic, and other Māori-non-Māori disparities, Māori leaders at a 1984 hui (conference) rejected assimilation or integration with newcomers and asserted that solutions lay in Māori being Māori. Kaupapa Māori is literally a Māori way. It is a response to the history of colonization in Aotearoa New Zealand that has seen Māori go from being ordinary to being the “other” in our own lands. Henry and Pene (2001, p. 237) describe Kaupapa Māori as “both. . . a resistance and reconstruction strategy and a culturally appropriate approach for Māori.” What then began in the late 1980s as Kaupapa Māori (by Māori, with Māori), research within Māori education has spread to other disciplines including health, where Kaupapa Māori health research has infiltrated quantitative and qualitative Māori health research and evaluation since the early 1990s. This research promotes a structural analysis of Māori health disparities that moves the discourse away from victim blaming to more fully understanding people’s lives and the determinants of Māori health disparities. Kaupapa Māori research has been described as a methodology (Smith 2012), an approach and a framework (Edwards et al. 2005). It has also been described as an inquiry paradigm (Cram et al. 2015; Cram and Mertens 2015), and it is this description that is pursued here.

In the 1980s, Guba and Lincoln (2005) drew on Thomas Kuhn’s work in the physical sciences to articulate inquiry paradigms within the social sciences. In their work, different paradigms are able to co-exist within the social sciences, and the different worldviews these paradigms represent are characterized by their philosophical assumptions about the nature of reality (ontology), the relationship between the knower and what would be known (epistemology), and what are considered to be appropriate approaches to systemic inquiry (methodology) (see also ► Chaps. 6, “Ontology and Epistemology,” and ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze”). Calling upon the language of paradigms in support of a Māori responsive research agenda echoes Linda Smith’s (2012) description of key concepts that are embedded within a culture that provide rallying points; drawing people together on cultural terms for dialogue about a purposeful dream. For Māori, these concepts include tino rangatiratanga (sovereignty) and whānau. Recently, a Whānau Ora (Māori family wellness) initiative has provided a key cultural concept that enables Māori to come together to work toward a common vision. If the language of paradigms can also be a way to draw peoples together for some sense of solidarity, purposeful dreaming, and transformation, then it may also serve a decolonization agenda (Cram and Mertens 2015). The use of the language of inquiry

paradigms builds upon the foundation laid by Chilisa (2012) and others of using this language to deconstruct White research paradigms and to pose an alternative Indigenous research paradigm. Describing Kaupapa Māori as a paradigm has also enabled a dialogue about decolonization to occur with other theorists who are committed to seeing research and evaluation contribute to social justice and equity around the world (Cram and Mertens 2015). This connection has firmly embedded axiology (ethics) as a key component of any inquiry paradigm (Mertens 2009). In the next part of this chapter, the assumptions of the four components of a Kaupapa Māori research paradigm (i.e., ontology, epistemology, methodology, and axiology) are defined. The potential role of Pākehā researchers within a Kaupapa Māori inquiry paradigm is touched upon in each section, with the proviso that the biggest thing a Pākehā researcher can bring is an open, reflexive mind and the knowledge that their world is just one of many.

2.1 Ontology: The Nature of Reality

Te ao Māori – the Māori world – is whakapapa – the genealogical ties that bind people with people, with the environment, and with the cosmos. Māori know this world through whakawhanaungatanga – the processes of understanding connectedness and relationships (Barlow 1991). Whakapapa means “to lay one thing upon another,” as in one generation upon the next. Barlow (1991, p.173) writes “[W]hakapapa is a basis for the organization of knowledge in respect of the creation and the development of all things.” This worldview emphasizes spirituality and spirit and the familial ties that bind people to one another. This is a reason for reciprocity as it is a way of honoring these relationships, with this described for Māori as an economy of affection (in contrast to a colonial economy of exploitation) (Henry and Pene 2001).

The nature of reality within Kaupapa Māori is represented by principles of Tino rangatiratanga (Self-determination), He taonga tuku iho (Cultural aspirations), Ako (Culturally preferred pedagogy), Kia piki ake i ngā raruraru o te kainga (Socio-economic mediation), Whānau (Extended family structure), and Kaupapa (Collective philosophy). An overview of these principles is given below (see also ► Chap. 88, “Culturally Safe Research with Vulnerable Populations (Māori)”).

2.1.1 Tino rangatiratanga (Self-Determination)

Māori sovereignty or self-determination is guaranteed in Article 2 of the Treaty of Waitangi. The importance of tino rangatiratanga has been emphasized at hui around the country since 1840. In the 1980s, tino rangatiratanga became part of the new Māori health movement where Māori claimed health initiatives as their own (Durie 1998). For example, at the 1994 Māori Health Decade gathering, Te Ara Ahu Whakamua, “[t]he most powerful and insistent message was the repeated call for Māori control and Māori management of Māori resources. . . ‘By Māori, for Māori’” (Te Puni Kōkiri 1994, p. 7).

2.1.2 He taonga tuku iho (Cultural Aspirations)

The assertion within Kaupapa Māori that being Māori is valid and legitimate, and to be taken for granted draws tikanga Māori (custom), te reo Māori (language), and mātauranga Māori (knowledge) into the contemporary environment as invaluable taonga (treasures) passed down from past generations (Smith 2012a). Within health services delivery, they are also seen as components of health practitioners' cultural competency to provide health care to Māori patients (Cram 2014).

2.1.3 Ako (Culturally Preferred Pedagogy)

Ako means both learner and teacher, with this principle describing culturally preferred pedagogies (both traditional and contemporary) that recognize that everyone has something to share and something to learn. Ako reinforces the importance of learning within tuakana-teina (older-younger) pairings and in groups. This might be, for example, learning to tie shoelaces or learning skills for the self-management of long-term health conditions.

2.1.4 Kia piki ake i nga raruraru o te kainga (Socioeconomic Mediation)

This principle recognizes that Kaupapa Māori mediation practices acknowledge and can successfully intervene in the socioeconomic disadvantage and negative pressures that are often experienced by whānau.

2.1.5 Whānau (Extended Family Structure)

As a way for Māori to organize their social world, the whānau has been a persistent structure in the face of colonization (Smith 2012). Whānau can still be defined as a collective concept that comprises three or more generations of the descendants of a significant marriage. Even when whānau are not contained within the same household they will still be whānau.

2.1.6 Kaupapa (Collective Philosophy)

A collective vision and commitment binds people together, whether they be kin whānau or kaupapa (agenda) whānau. It is kaupapa that connects whānau, hapū (subtribe), Iwi (tribe), and Māori community collectives to their aspirations for positive cultural, economic, social, and political well-being.

In summary, Kaupapa Māori ontology articulates what it means to be Māori, to be fully human within a Māori world. This world is about relationships and connectedness to other people, to the environment, and to the cosmos. It is a world that thrives within an economy of affection. While Māori researchers may be immersed in this world and be able to speak as part of a transdisciplinary team undertaking Kaupapa Māori health research, it is important that Pākehā researchers on the team also undertake to become familiar with this world – not so they can fully represent it but rather so they can support their Māori colleagues and advocate for their right to live, breathe, and be Māori within a research context.

2.2 Epistemology: Relationship between the Knower and What would be Known

Mātauranga Māori, often translated as knowledge, is a Māori tool for organizing and thinking about knowledge, including about our place in the world. As Tau (2001, p. 73) writes: “[M]atauranga Māori is simply the epistemology of Māori – it is what underpins and gives point and meaning to Māori knowledge.” There is a sacredness about mātauranga Māori and, therefore, also the cultural practices tied to knowledge and learning (Smith 2012). The purpose of knowledge is to serve and uphold the mana (status) of the community. Traditionally, not all knowledge was available to everyone. Rather, some knowledge was available to all peoples to enable day-to-day living, while other tapu (sacred) knowledge was entrusted to only a few who would protect it and use it appropriately (Smith 2012). The transmission of this knowledge was, therefore, within Māori schools of learning, under the tutelage and guidance of tribal experts (Te Awekotuku 1991).

The cultural practices that link knowers to what would be known invariably acknowledge and work within a web of relationships that is the Māori world (see above, Ontology). The meandering (rather than linear) pathways of these connections and relationships are embedded within Indigenous languages, with knowledge coming from keen observation and interpretative messages (Deloria 1999) and reflexive learning cycles (Henry and Pene 2001). As Brant Castellano (2004, p. 98) writes: “Aboriginal knowledge has always been informed by research, the purposeful gathering of information and the thoughtful distillation of meaning.” Thus, research becomes “**re-search**,” as explained by Aboriginal educator Bob Morgan; it is about searching familiar pathways with a new inquisitiveness, new questions, new tools, and new companions. In addition to formal inquiry, epistemology is also an everyday occurrence, where events and objects can be looked at anew.

A key challenge to mātauranga Māori is epistemological racism. Scheurich and Young (1997) write that “White racism or White supremacy became interlaced or interwoven into the founding fabric of modernist western civilization” (p. 7) through “racially biased ways of knowing” (p. 4). The result has been the exclusion of other non-White epistemologies including mātauranga Māori, and the consequential negative impacts on Indigenous and minoritized peoples around the world (Smith 2012). The dual task of Kaupapa Māori research is, therefore, to engage with mātauranga Māori as well as with the deconstruction and challenging of White epistemology (Smith 2012a).

Critically, for Māori health, the emphasis on illness within the health sector needs to continue to be challenged so that other knowing about health and well-being can be fully recognized. Māori cultural aspirations are for holistic health and well-being that includes physical, mental, and spiritual health and extends to economic security and whānau support (Te Puni Kōkiri 1994), a good education and a healthy home free from violence, and political representation and environmental protection (Pomare et al. 1995). Holistic models of Māori health, including Te Whare Tapa Wha (Durie 1985) and Te Wheke (Pere 1988), speak to these aspirations. They also align with other Indigenous peoples where health is equivalent to the “harmonious

coexistence of human beings with nature, with themselves, and with others, aimed at integral well-being, in spiritual, individual, and social wholeness and tranquility” (UN Permanent Forum on Indigenous Issues 2009, p. 157). Likewise, the recent Whānau Ora (Māori family wellness) initiative acknowledges and aims to strengthen the connectedness of whānau members, as well as increase the inclusion of whānau within society. Within this initiative, the well-being of whānau is measured through a holistic framework that acknowledges Māori conceptions of health and well-being. The six major whānau goals developed by the Taskforce on Whānau-Centered Initiatives (2010, p. 43) are whānau self-management, healthy whānau lifestyles, full whānau participation in society, confident whānau participation in te ao Māori (the Māori world), economic security and successful involvement in wealth creation, and whānau cohesion.

In summary, a Kaupapa Māori research epistemology is mātauranga Māori – Māori knowledge. In order to make space for mātauranga Māori the dual task of Kaupapa Māori research is to explore mātauranga hauora – knowledge of wellness – and critique other knowledge systems that challenge and undermine that knowledge. Pākehā researchers can support a Māori kaupapa by enquiring after the knowledge systems that challenge mātauranga Māori. For example, in a project on Māori patients’ interactions with Pākehā general practitioners, the Māori researchers talked with patients while the Pākehā researchers talked with general practitioners in a parallel research process. This gave insight into mātauranga hauora as well as Pākehā discourses that supported or undermined it within primary health care (Cram et al. 2006).

2.3 Methodology: Appropriate Approaches to Systemic Inquiry

Methodology is about how to find things out, how to gain knowledge (Guba and Lincoln 2005; see ► Chap. 97, “Indigenous Statistics”). Kaupapa Māori methodology informs the selection of health research projects that have the potential to make a difference for Māori. This makes research both culturally prescribed and culturally acceptable. Linda Smith (2012) lists a series of questions that can be asked about research that can support the decision-making of both researchers and Māori communities about whether a project should proceed. These include questions about who defined the research question or problem, who will benefit or possibly be negatively impacted by the research, and who will gain knowledge from the research. The time has passed when researchers are in sole control of a research agenda. Now the expectation is that Māori health research should respond to Māori needs, priorities, and aspirations (Cram 2015).

Methodological considerations, especially the questions that research is aiming to answer, also inform the choice of research methods. Paipa et al. (2015) recommend that methods be selected for Kaupapa Māori evaluations using the principles of whakapapa (kinship connections), whakawhanaungatanga (making connections), whakawātea (a cleansing approach), whakaae (agreement), and whakamana (enhancement of authority). This will help ensure that the chosen methods will align

with Māori values and make cultural sense. For example, researchers at Te Rōpū Rangahau Hauora a Eru Pōmare and Ngāti Kahungunu Iwi Incorporated (Ngāti Kahungunu tribal authority) used multi-method research to examine the health effects on Māori of employment loss due to factory closure. These included Kaupapa Māori epidemiology (Keefe et al. 2002), focus groups and interviews (Cram et al. 1997), and document review (during an evaluation) (see Cram and Mertens 2015 for an overview of this research).

In summary, methodology is responsive to the questions asked by Māori about the mission and vision of the research they are being asked to be involved in. Both Māori and Pākehā researchers need to be skilled enough to rise to this challenge – bending method rules where they need to be bent in order for research to be culturally relevant while at the same time ensuring that the research is also scientifically credible and valid.

2.4 Axiology: Nature of Ethics

Guba and Lincoln (2005) did not explicitly refer to axiology in their description and subsequent discussion of paradigms – confining themselves primarily to ontology, epistemology, and methodology. Axiology – what is done to gain knowledge, and what that knowledge will be used for – has been brought to the fore in Mertens’ (2009) transformative paradigm.

For Māori, ethical obligations within research are about the maintenance and strengthening of relationships, and the cultural processes that help ensure this. “Concern for people’s own well-being and prosperity ensured the observation of ethical practice, because a scholar was accountable to [their learning] community” (Te Awēkotuku 1991, p. 8). This is similar to the operation of a communal ethic within Canadian Aboriginal communities that is “intimately related to who you are, the deep values you subscribe to, and your understanding of your place in the spiritual order of reality” (Brant Castellano 2004, p. 103). A key element of the Kaupapa Māori axiological assumption is attention to the cultural norms and protocols of the community in which research takes place. Seven “community-up” values describe ethical protocols that guide research practice (Pipi et al. 2004; Cram 2009; Smith 2012) (see Table 1 for an overview).

2.4.1 Aroha ki te tāngata: A Respect for People

- *About allowing people to define their own space and to meet on their own terms*

The essential characteristics associated with relationships are that they are respectful and trusting. Rituals of first encounter enable researchers to negotiate the space between themselves and those they want to involve in their research (Irwin 1994). Kaumātua (Māori elders) can assist researchers to make appropriate judgments and decisions within cultural spaces, including leading customary practices. For example, the E Hine project – a Kaupapa Māori health research on young Māori women (less than 20 years of age) having babies – has been guided by a Kāhui Kaumātua

Table 1 “Community-Up” approach to defining research conduct

Cultural values (Smith 1999)	Researcher guidelines (Cram 2001)	Kaupapa Māori health research practices
1. Aroha ki te tāngata	Be respectful – Allow people to define their own space and meet on their own terms	<ul style="list-style-type: none"> • Meet at places convenient to communities • Use cultural protocols to bridge the space between researchers and community • Engage elders to facilitate rituals of encounter • Acknowledge and strengthen connections
2. He kanohi kitea	Meet people face to face, and to also be a face that is known to and seen within a community	<ul style="list-style-type: none"> • Be known to communities • Be respectful and professional when encountering people known in other roles • Allow Māori research team members to take a lead • Budget for regular meetings in community
3. Titiro, whakarongo... kōrero	Look and listen (and then maybe speak) – Develop understanding in order to find a place from which to speak	<ul style="list-style-type: none"> • Use all your senses during encounters • Encourage all peoples to participate • Know the value of silence • Feedback on the key points you are taking away
4. Manaaki ki te tangata	Share, host, and be generous	<ul style="list-style-type: none"> • Look after visitors, especially those uncomfortable in research contexts • Ensure needs and concerns are canvassed and addressed • Offer appropriate support • Ensure that attendance is cost neutral for community members
5. Kia tūpatō	Be cautious – Be politically astute, culturally safe, and reflective about insider/outsider status	<ul style="list-style-type: none"> • Know a community’s history and current political standing • A research role is an “outsider” role, even when researchers are from a community • Be guided by community leaders about the appropriateness of methods • Ensure that participants and researchers are kept safe
6. Kaua e takahia te mana o te tāngata	Do not trample on the “mana” or dignity of a person	<ul style="list-style-type: none"> • Choose research methods that authentically represent lived realities • Allow time for people to participate in genuine ways • Ensure researchers have the skills to engage with community members • Maintain the integrity of research

(continued)

Table 1 (continued)

Cultural values (Smith 1999)	Researcher guidelines (Cram 2001)	Kaupapa Māori health research practices
7. Kia māhaki	Be humble – Do not flaunt your knowledge; find ways of sharing it	<ul style="list-style-type: none"> • Be honest about what the researchers do not know • Return information and knowledge to communities • Support communities to utilize research knowledge • Be responsive to community health priorities, and work to advance research in those areas

(Elders Group) who provide cultural advice and also accompany the researchers during their consultation and feedback meetings. These elders hold knowledge of relationships among community members, and among tribal groups. This project also sought input from a Rōpū Māmā – a young Māori mothers advisory group – to ensure that the project was responsive to participants' lived realities (Lawton et al. 2013).

Research teams for other Kaupapa Māori research projects have been guided by team members who have the necessary cultural expertise (Pipi et al. 2004). For example, many of the researchers on projects looking at the health impacts of Māori job loss had genealogical connections with this tribe as well. The researchers noted that their whakapapa (genealogical connections) only got them “in the door”; it was their research skills and professionalism that prevented them from being shown out that door by Māori communities still wary of research (Cram et al. 1997).

2.4.2 He kanohi kitea: A Face That Is Known

- *About the importance of researchers being known to the people*

Researchers are expected to be clear and honest about their research, including how the research findings will be used and how participants and other community stakeholders will be kept informed about the findings. Maori communities call upon researchers who intend to conduct studies in their communities to come face-to-face with them (Cram 2009), and to explain the nature of the research and the relationships between the researchers and tribe or community. This allows potential research participants to use all their senses to assess the advantages and potential disadvantages of their involvement. These meetings may also signal the beginning of a relationship that will extend beyond the end of the research project itself. The research on factory closure described above, for example, is a series of research projects conducted within a 25-year research relationship with Ngāti Kahungunu.

2.4.3 Titiro, whakarongo . . . kōrero – Look, Listen . . . Speak

- *About taking the time to become accustomed to a setting in order to find your voice*

This practice is about allowing time for people to discover each other's intricacies, so that mutual thinking can emerge between the parties involved in a research project.

Researchers should use all their senses to engage with communities, and also when undertaking research with Māori participants. There is value in silence and also in being able to offer appropriate responses and support. For example, evaluation encounters with Māori organizations in the 1990s were sometimes difficult because of an organization's past experiences with evaluators. Time taken to sit and to listen to the concerns of these organizations may have delayed the start of an evaluation, but was time well spent getting to know one another so that when the evaluators spoke they did so having gained some insight into the organization's reality. Evaluation relationships around issues of healthy activity and eating in one case, and issues of intimate partner violence in another case then grew into three to 6 year collaborations to explore and revise what works for Māori (Cargo and Cram 2003).

2.4.4 Manaaki ki te tangata: Host People

- *About having a collaborative approach to research, research training and reciprocity*

In research settings researchers may have something meaningful to contribute, as information flows in both directions. This occurred in Kaupapa Māori research with whānau about their children's asthma. The interviewing researcher was a nurse who could answer health questions asked by whānau, and who could connect whānau with a Māori asthma health organization that was under the leadership of another member of the research team (Jones et al. 2010). This enabled the research team to be responsive to whānau, rather than just one-way recipients of whānau information.

Manaaki is also expressed through koha or an offering to research participants to thank them for taking the time to be involved in the research project. This offering might be money or vouchers (e.g., petrol or grocery vouchers), books, or food. It is not an incentive to be involved and, in many cases, participants will not be aware they will receive such a thank you until after their research participation has ended.

2.4.5 Kia Tūpato: Be Careful

- *About being politically astute, culturally safe and reflexive about our insider/outsider status*

Kia tūpato is a caution to researchers that they need to take care, especially when negotiating spiritual spaces within their research. Research on Māori sudden infant death syndrome that involved interviewing whānau, especially Māori men who had lost a child, allowed participating whānau to follow their preferred rituals of whakawhanaungatanga (establishment of relationships) and karakia (prayer) so that the research space would be safe for them. Case workers were also present during these interviews to provide additional support to whānau (Edwards et al. 2005). One of the projects looking at the impact of employment loss on Māori involved accessing ex-workers' personnel records for an epidemiological study. The researchers appreciated that some workers had passed away and some were ill so they invited an elder to bless the records before any were looked at (Keefe et al. 1999).

2.4.6 Kaua e takahia te mana o te tangata: Do Not Trample on the Status of the People

- *Take care to acknowledge and respect people's roles and responsibilities*

Respect for people's status must filter through all stages of a research project, beginning with Kaupapa Māori research being responsive to Māori needs, priorities, and aspirations (Cram 2015). For example, research relationships should first be established with the tribal authorities for the regions that researchers want to work in. People also need to be able to take the time necessary for consultation and decision-making, with researchers ensuring they have the skills on their team to ensure this happens. This includes being flexible about the choice of research methods, or about the inclusion of additional methods that will give a community confidence its views will be well represented.

2.4.7 Kia māhaki: Be Humble

- *Do not flaunt your knowledge; share it and use your qualifications to benefit a community*

This final practice is about sounding out ideas with people, disseminating research findings, providing community feedback that keeps people informed about the research process and the findings. When research requests are outside researchers' discipline and expertise, they need to be honest about this, and then work with communities to connect them with researchers who can help. When research is conducted with a community there should be clear communication back to that community about the findings, along with support for any advocacy the community wishes to then take to improve their health and well-being. Communities must decide what is empowering, with researchers supporting when they can.

Shared knowledge... is one of the key tools for empowering the people... the results of research [should be] made available to form part of the knowledge base of the people and to help them make decisions. (Mutu 1998, p. 51)

In summary, the community-up research practices provide guidance to researchers about engaging with communities and participants to both design and deliver Māori health research. They were first proposed as a guide for both Māori and Pākehā researchers. They have since become an example of how Māori might describe their views of good research practices.

3 Conclusion and Future Directions

A Kaupapa Māori inquiry paradigm is transformation space as it asserts the validity and legitimacy of being Māori and the right of Māori to live lives and undertake research that facilitate Māori health and well-being. At a high level, Kaupapa Māori

has much in common with the theories of other groups who are seeking to enlarge their own worlds within an oppressive and marginalizing White “mainstream,” for example, feminist, African-American, and deaf communities (Mertens 2009). The calling into existence of these worlds remakes these peoples as fully human, valuable contributing members of society, and helps ensure their cultural survival. At a local level, Kaupapa Māori addresses the oppression of Māori within their own lands, and the loss of those lands due to broken treaty guarantees. In this way it is unique. The justice Kaupapa Māori seeks is decolonization, including the return of stolen lands and resources as essential to Māori health and well-being. It is a decolonization project that seeks the return of Aotearoa.

This chapter has used the language of inquiry paradigms to distil Kaupapa Māori into component parts of epistemology, ontology, methodology, and axiology. The language of paradigms allows for this segmentation, but this is a device only rather than a truth about our world. It has allowed the examination of how Māori and (briefly) Pākehā researchers might be involved in a Māori agenda of health research that desires Māori health in its fullness, as it can be within a Māori world. In addition to the return of Māori land, this world is about the strengthening of Māori connectedness to one another, to the environment, and to the cosmos. It is about the revitalization of an economy of affection that was displaced during colonization by a capitalist economy (Henry and Pene 2001).

It is essential that social change is facilitated in a way that is commensurate with the day-to-day realities of the people affected (Cram 2015). This cannot be an exercise that is undertaken in, and confined to, the academy. Such moves turn the Indigenous transformative goal of sovereignty through decolonization into a metaphor and “kills the very possibility of decolonization; it recenters whiteness, it resettles theory, it extends innocence to the settler, it entertains a settler future” (Tuck and Yang 2012, p. 3). A Kaupapa Māori inquiry paradigm must, therefore, always be vigilant about the appropriation of decolonization and the distraction of health researchers away from a mission of eliminating Māori health disparities and enabling Māori to live in health and wellness as it is defined within a Māori cultural view. Health disparities will continue until there is also social, economic, and political equity for Māori (Durie 1998).

The future direction for Kaupapa Māori health research is, therefore, challenging disparities and seeking to fully represent Māori realities and aspirations. While the capacity of Māori health researchers has grown over the past 25 years, there is still a need for Pākehā health researchers who are willing to contribute their skills and expertise to this mission. The chapter did not begin from the point of view of Pākehā researchers because this is not the right starting point. Cross-cultural research is not about non-Indigenous researchers learning the passwords and byways that allow them to access Indigenous communities. Rather, it is about these colleagues starting from a place of commitment, combined with willingness to learn that can only come about when they realize that the privileged world they inhabit has been built on broken promises and Māori loss and marginalization. This may prompt guilt or anger on their part but, more helpfully, it should prompt commitment and questions

about what they might do to facilitate the re-inclusion of Māori within Aotearoa New Zealand.

Waiho i te toipoto, kaua i te toiroa.
Let us keep close together, not far apart.

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Culturally Safe Research with Vulnerable Populations (Māori)

88

Denise Wilson

Contents

1	Introduction	1526
2	The Significance of Culture	1527
3	Māori and Research	1529
4	Research at the Interface	1531
5	Culturally Responsive and Safe Research	1535
6	A Framework for Culturally Safe Research	1535
7	Conclusion and Future Directions	1540
	References	1541

Abstract

Vulnerable populations are often subjected to some form of social marginalization. This contributes to persistent inequities in their social and health outcomes, and differences in their access to and use of necessary services. Researchers' decisions and the research processes they utilize can further increase their risk of vulnerability and marginalization. Historically, Māori (indigenous peoples of Aotearoa New Zealand) experiences with research often yielded little benefit for them, instead frequently reinforcing negative stereotypes and perpetuating deficit explanations and inaccuracies. Today, many Maori remain suspicious of researchers and their agendas and are reluctant to engage in research. Yet, quality evidence and generating accurate “stories” are crucial to inform optimal strategies to resolve persistent social and health inequities. Nonetheless, evidence founded on dominant cultural research paradigms and sociocultural realities and interpretations can worsen people's vulnerability and marginalization within social and health research contexts. Creating culturally responsive and safe spaces and research contexts with Maori, and others vulnerable within research settings,

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are needed to minimize participants' vulnerability and marginalization and counter unhelpful constructions about them. In this chapter, the importance of understanding the impact differing worldviews can have on researchers, research methodology, and research conduct with vulnerable populations will be discussed. Strategies will be presented aimed at minimizing the vulnerability of those participating in or targeted for research. A framework based on the concepts of partnership, participation, protection, and power is provided to assist researchers' cultural responsiveness, getting the research story right, and importantly, to improve the utility of their research.

Keywords

Indigenous research · Cultural responsiveness · Cultural safety · Māori · Māori-centered · Kaupapa Māori research

1 Introduction

Undertaking research that accurately portrays “the story” of those participating in the research, and which is conducted and interpreted in socially and culturally responsible ways, is a fundamental requirement for undertaking cross-cultural research, particularly with those considered vulnerable (Liamputtong 2010). For the purposes of this chapter, vulnerable groups are those peoples whose strengths and positive attributes are generally overlooked, and who are confronted with differential risks and health burdens in comparison to others living in their community or country. Within the context of research, this means those considered vulnerable, marginalized or belonging to minority groups are potentially at risk of further burden by research that is conducted on them (not with them) and interpretations that bear little or no resemblance to their realities. Oftentimes, those who belong to “vulnerable” groups live with ongoing health and social inequities (Ruger 2008). Addressing these inequities requires understanding the people belonging to these groups, their life circumstances, and the sometimes multitude of factors impacting their daily lives. In order to understand and then produce useful knowledge and interventions requires culturally responsive and safe research – researchers' decisions and actions can inadvertently increase people's vulnerability and serve to marginalize them within and throughout the research process.

Indigenous peoples globally can be considered vulnerable within a background of persistent social and health inequities they face, and their subjection to discriminatory research processes that have overlooked the significance of their culture (Smith 2012; see also ► Chap. 15, “Indigenist and Decolonizing Research Methodology,” ► 87, “Kaupapa Māori Health Research,” ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research,” ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,” ► 97, “Indigenous Statistics,” and ► 106, “Ethics and Research with Indigenous Peoples”). Moreover, researchers have often disregarded and disrespected people's important cultural traditions and practices. There are numerous accounts of research undertaken in

disrespectful and demeaning ways that have not only negated the importance of the people but “trampled” on their cultural ways and their status as indigenous peoples (Chilisa 2012; Smith 2012; Walter and Andersen 2013). Linda Smith (2012, p. 1) notes the impact of researchers on Māori as a process that “. . .stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful.” “Outsiders” have come into indigenous communities as detached observers without establishing meaningful relationships with the people. It is not unusual for indigenous peoples to endure situations but at the same time withhold or filter information they share. Researchers have then gone away and analyzed their observations with no real understanding of their accuracy and the nuances of language and cultural practices. Such approaches to research produce research that lacks cultural responsiveness, and can only be considered culturally unsafe.

The aim of this chapter is to assist researchers developing their cultural responsiveness, getting the research story right, and importantly, to ultimately improve the utility of their research for indigenous peoples. In this chapter, Māori (the indigenous peoples of Aotearoa New Zealand) will be referred to and links with other indigenous peoples who have been colonized made where appropriate. To begin an overview of what culture is presented. Thereafter, the impact of differing worldviews on research, the selection of research methodology, and the way in which research is conducted is discussed. The significance of the role that culture plays when planning and undertaking research is explored briefly, within the context of culturally responsive and culturally safe research practice for Māori, the indigenous peoples of Aotearoa New Zealand. Strategies aimed at minimizing (and ideally eliminating) participant vulnerability will be presented together with a framework based on the concepts of partnership, participation, protection, and power (see also ► Chap. 87, “Kaupapa Māori Health Research”).

2 The Significance of Culture

Culture refers to the shared beliefs, values, and everyday practices groups of people undertake, influenced by their unique worldview (Wilson and Hickey 2015). It prescribes expectations related to interactions, behaviors, and protocols to guide the way things are done – for instance, processes of engagement with those not belonging to the group under study. It differs from the concepts of ethnicity and race. Ethnicity refers to larger groupings of people belonging to different “cultural” groups based on a common heritage or nations (for example, Pacific peoples, Greek, or Asian). On the other hand race classifies people based on their physical features (such as Caucasian, Polynesian, Asian, and Melanesian) (Bhopal 2004).

Individuals grow up within a cultural milieu created by their family of origin, and influenced by those they interact with, for instance other groups of people with differing cultures (such as those based on age, gender, generation, sexual orientation, occupation, socioeconomic status, ethnic origin, migrant or refugee experiences, spiritual or religious beliefs, and disability (Nursing Council of New Zealand 2011)). The ensuing interactions with differing and similar groups over time shapes and modifies people’s culture in addition to the social and technological changes that in

turn alter what behaviors are considered acceptable and what is expected. In this way, culture is dynamic and contributes to the growing contemporary diversity that occurs not only between cultural groups but within them. Importantly, it influences how people see and understand the world. If we ignore people's culture when embarking on research, its findings and outcomes may not fully realize the intended aims. The message is that culture counts, and that it can "eat" the best planned research strategy if ignored. Researchers are, therefore, advised to give serious consideration to how they include those people from different cultures to ensure their cultural needs are incorporated into planning, implementing, and reporting their research.

Globally, indigenous peoples share similarities in their worldviews and cultural practices. Generally, they are defined by a holistic and spiritual view of the world, which is defined by their whakapapa (genealogy), relationships, and interactions with not only living people but also their ancestors, living creatures, and the environment (Battiste 2000; Chilisa 2012; Sherwood and Kendall 2013). A defining feature that sets indigenous peoples aside from those belonging to the dominant western cultural groups is their collective orientation and the associated responsibilities and obligations to others. This contrasts with the dominant cultural focus on individualism, first and foremost.

The nuances and subtleties of culture and its concepts are embedded in language, which can be considered the window to people's culture. Thus, how to best access and understand people's culture is an essential consideration when planning and conducting research. Marsden (cited in Royal 2003) highlights the importance of culture, stating:

Cultures pattern perceptions of reality into conceptualisations of what they perceive reality to be; of what is to be regarded as actual, probable, possible or impossible. These conceptualisations from what is termed the 'worldview' of a culture. . . lies at the very heart of culture, touching, interacting with and strongly influencing every aspect of the culture. (p. 56)

Vulnerable people are subjected to services that are constructed and delivered based on evidence informed by dominant epistemologies which privilege how information is gathered, analyzed, and interpreted. This is referred to "epistemological domination," whereby one epistemology is exclusively privileged over another – in the case of this chapter non-Māori western epistemologies are promoted over Māori indigenous epistemologies (Moewaka Barnes et al. 2008; see also ► Chap. 87, "Kaupapa Māori Health Research"). Ironically, indigenous researchers using indigenous methodologies are often required to still conform to and address dominant Western research requirements.

Ignoring the significance of culture increases the risk of producing research outcomes that lack relevance and utility. Such an approach disregards people's historical and everyday realities and circumstances, risking research outcomes that either lack relevance or are inappropriate. Importantly, researchers need to understand these historical and contemporary dimensions and how they identify and bridge the "gap" existing between the researchers' cultural location and that of those being researched. Researchers can have the best intentions and strategies,

but framing and planning research with vulnerable populations from a different worldview is often driven by hegemonic and unconscious biases that promote ignoring the crucial role of culture.

3 Māori and Research

To understand the need for culturally responsive and safe research approaches, there is also a need to understand the historical and contemporary realities of those considered vulnerable, such as indigenous peoples similar to Māori. Without question, colonization has had significant and damaging effects on Māori, comparable to indigenous peoples in Australia, Canada, and the United States. Undoubtedly, colonization has had detrimental effects on indigenous peoples (Sherwood 2013). The long established ways of observing, knowing, and understanding the world Māori possessed was systematically replaced by “new” scientific ways of knowing – ignoring the crucial role of culture. Colonization and imperialism led to historic injustices, which have in turn created the social milieu to perpetuate ongoing contemporary socioeconomic and political disenfranchisement (Smith 2012). Accompanying the colonization of Aotearoa New Zealand was the systematic invalidation of indigenous knowledge and ways of knowing that sustained indigenous communities for hundreds of years, handed down from generation to generation. The dispossession of land (people’s *tūrangawaewae* – a place to stand in the world), language (*te reo Māori*), disconnection from supports, deculturation of protective cultural practices, along with widespread depopulation through disease and warfare contributed to the loss of Māori ways of knowing and being in the world (Durie 1998). Policies of assimilation further aided this loss, such as banning *te reo Māori* being spoken in schools, while urbanization in the 1950s and 1960s removed people from their vital *whānau* (extended family) supports and cultural practices. Legislation, such as the *Tohunga Suppression Act 1907*, banned the practices of traditional healers which led to the loss of important cultural knowledge. Consequently, *mātauranga Māori* (traditional Māori knowledge) was invalidated and demeaned, instead replaced by Western scientific paradigms that became the prevailing and accepted way of viewing knowledge (Durie 1998).

It was from dominant Western epistemological stances that researchers repeatedly characterized Māori within deficit constructs, regularly depicting them negatively. Māori have been subjected to generations of research about them but not with them being adequately involved. Subsequently, research has been considered to be of little or no benefit or relevance to Māori, particularly when based on inaccurate interpretations that becomes common understandings and “truths.” This most often arises from researchers functioning on unconscious biases and lacking essential cultural insights to accurately collect, analyze, and interpret the data. Such approaches circumvent “getting the story right” (Smith 2012). Moreover of concern are the culturally inappropriate and unacceptable processes researchers often use to engage with Māori and obtain their information. Jahnke and Taiapa (1999) highlight the importance of culture, stating:

Knowledge which makes sense in one particular context cannot always be understood through the tools that govern the understanding of other belief systems and worldviews. (p. 41)

Often, researchers left with inaccurate and incomplete information, all the while having “trampled” on the mana (status and esteem) of Māori communities. Understandably, many Māori to this day remain suspicious of researchers’ and research agendas.

Research is important to inform responses to addressing the serious and persistent inequities Māori suffer in their health and social outcomes, as well as their experiences and the quality of health service access and use. Research findings and recommendations based on Western paradigms and research approaches do not always work for Māori, particularly when they promulgate uninformed and unhelpful discourses. This is primarily because such findings can be devoid of any analysis or consideration of the competing intersections of cultural relevance and multiple oppressions. Research undertaken without cultural insights and relevance, and a critical understanding of the historical and contemporary social and health inequities that indigenous peoples are faced with, ignores the ongoing systemic issues they encounter when accessing health or social services.

For instance, while “big picture” research using quantitative methodologies can show us what is happening on a large scale, it is unable to provide the contextual issues that are important for effectively addressing disparities and inequities in social and health well-being. However, smaller qualitative, culture-based research studies using appropriate processes and methods that seek people’s actual experiences can provide greater insight and offer counter-understandings than the existing prevailing ones (Liamputtong 2010). For example, the research mentioned in Box 1 demonstrates the systemic and health-provider issues young pregnant Māori women encounter when seeking early maternity care which are often absent in “mainstream” research studies. This study utilized Māori research approaches which enabled researchers to access and gain the trust of this group of young Māori women, who are ‘known’ to avoid services when they are confronted with or anticipate negative responses from health-care providers.

Box 1 Countering Prevailing Discourses About Inequities

In Aotearoa New Zealand, pregnant Māori women less than 20 years of age are at higher risk of poor maternal and infant outcomes. Negative portrayals are prevalent about young Māori women who are pregnant, particularly because they are seen to present late and “fail” to attend early maternity care, which is believed to contribute to increased risk of poor outcomes for both mother and baby. Such portrayals position “blame” onto vulnerable young women and is frequently supported by evidence generated using a dominant cultural lens. Thus, “common” understandings promulgated are that these young Māori

(continued)

Box 1 (continued)

women are remiss and somewhat neglectful regarding their own health and that of their babies. Makowharemahihi et al. (2014) interviewed 44 young Māori women under 20 years of age who were pregnant or recently pregnant using a kaupapa Māori research approach. They reported a contrary “story” indicating that the majority of these women accessed health care services early to confirm their pregnancy, but they received inadequate information about how to navigate the maternity care system. Also evident were missed opportunities and failure to respond by health-care providers in assisting these women to access maternity care (usually a midwife). This in turn led to fragmented maternity care and inhibited them having a seamless pathway of care. Those health-care providers who provided practical assistance to access a lead maternity carer and women with supportive whānau and friends were better able to access seamless maternity care earlier in their pregnancy. This study using a Māori approach to gather and analyze data shows that contrary to common understandings of healthcare providers, young pregnant Māori women are proactively connecting with primary health care services early – they often encounter barriers difficult to overcome.

Makowharemahihi et al. (2014).

4 Research at the Interface

Research lacking connection to Māori realities will not result in the expected impact, and therefore, researchers must be cognizant of local Māori cultural values and practices (Durie 2004). The research interface enables a place for the best approach to be used to answer a research question(s) being investigated that draws on both indigenous methodologies and knowledge and suitable western research methodologies and/or methods. It is a space in which mutual dialogue and negotiation can occur, and whereby culturally appropriate and safe processes and actions can be established – a place without contest or challenge where indigenous researchers meet with those researchers who work from western methodological epistemologies to ensure research is designed to best reflect indigenous realities (see Fig. 1).

For Māori, the research interface is contingent on healthy bicultural relationships based on Te Tiriti o Waitangi that recognizes and respects Māori culture and peoples. The Treaty of Waitangi in 1840 was signed by representatives of the British Crown and Māori chiefs. This Treaty sets out an agreed relationship with expectations between Māori and the British Crown. Nevertheless, significant differences exist between Te Tiriti o Waitangi (the Māori language version) and the Treaty of Waitangi (the English language version), although the English version is deferred to officially. However, Māori often refer to Te Tiriti o Waitangi, which is the version their ancestors signed. In signing Te Tiriti o Waitangi, they ceded governorship (not



Fig. 1 The research interface (Note: Adapted from Wilson and Neville (2009))

sovereignty) of their lands and were guaranteed the rights of tino rangatiratanga (self-determination), to sell their land, have equitable outcomes, and be protected. Historically, the rights enshrined within the Treaty have not been upheld, and until the 1960s, it was generally not honored breaching the rights of Māori (Hudson and Russell 2009; Wilson and Haretuku 2015). Breaches of the Te Tiriti o Waitangi have compromised the cultural identity of Māori and for many denied the opportunities to access te ao Māori (the Māori world). Cram (2012) claims that breaches of Te Tiriti o Waitangi are the origins of Māori overrepresentation in poor social outcomes (see also ► Chap. 87, “Kaupapa Māori Health Research”).

Establishing healthy bicultural relationships based on the notion of reciprocity ensures research processes and outcomes are:

- Beneficial to Māori
- Inclusive of Māori values, aspirations, and needs
- Privilege an indigenous Māori worldview
- Māori retain self-determination and control over the research to make sure their interests are protected

Such bicultural relationships are premised on the notion of equitable relationships between indigenous groups, like Māori, and those undertaking the research. The research relationship, according to Hudson and Russell (2009), should be founded on the equal status of all parties, the veracity of the engagement, and equitable outcomes – it can be considered a framework for not only balanced relationships but also for restoring power to Māori.

Keeping central and prominent the indigenous cultural imperatives of those being researched throughout the research process is crucial to honor the rights embedded within Te Tiriti o Waitangi. In Aotearoa, ethical review processes require researchers to demonstrate their responsiveness to Māori based on the principles of the Treaty of Waitangi – that is, partnership, participation, and protection (discussed later in the chapter).

Māori research methodologies, such as Kaupapa Māori Research (see for example, Smith 2012), Māori-centered research (for instance, Durie 1997; Wilson 2004), and their several variations, represent strategic Māori decolonizing and reclaiming the Māori research space and regaining control over research about them. It is about research with, by, and for Māori, particularly kaupapa Māori (Smith 2000). It is fundamentally nested within te ao Māori (Māori worldview) and informed by mātauranga Māori and Māori beliefs, values, and practices. It normalizes te ao Māori (rather than excludes as seen in western scientific approaches) within a research context (Moewaka Barnes 2000). Smith (2000, 2012) identifies the following dimensions of kaupapa Māori research:

- It is about being Māori,
- It is grounded in Māori viewpoints and ideologies,
- It normalizes the validity and legitimacy of Māori language and culture, and
- It is concerned with tino rangatiratanga (self-determination/autonomy) over Māori well-being.

Smith also locates kaupapa Māori within localized critical theory, which critiques the power structures and social inequities within the unique historical and contemporary contexts Māori experience. While the emancipatory goals of kaupapa Māori is somewhat debated (see Bishop 1998, for example) given the failure to meet these goals, it does help to interrogate the unique local contexts and social and health inequities confronting Māori.

Without doubt, there are numerous variations within how kaupapa Māori research is expressed, which is reflective of Māori in general – Māori are not a homogenous group of people, but rather a diverse people with variations on how they see the world from iwi and hapū to iwi and hapū. Added to this diversity is the contemporary reality for many with varying connections culturally to their Māori whakapapa. According to Moewaka Barnes (2000), it is a “distinctive” approach. For example, Irwin (1994) and Bishop (1996) utilized whānau for the supervision and way in which they structured their research, and Bishop’s work is based on whakawhānaungatanga. More recently, constructivist forms of kaupapa Māori have also emerged (Eketone 2006; Walker et al. 2006).

Māori-centered research is underpinned by three cornerstones to ensure Māori interests in research are upheld. These are, whakatuia (integration), whakapiki tangata (enablement), and mana Māori (control) (Durie 1997). This means that under the guidance of indigenous researchers, Māori cultural values, practices, and processes are integrated into the research design and processes, Māori participation is ensured, and Māori control over the research and its outcomes is safeguarded. Box 2 shows an example of research where researchers leading a project erroneously interpreted, and then used Māori-centered research without ensuring these three cornerstones informed the development of the research. An example is then presented using the three cornerstones of Māori-centered research to illustrate culturally responsive research practice.

Box 2 Moving from Flawed to Culturally Responsive Practice

Exemplar	Flawed practice	Culturally responsive practice
<p>The research team designed a study building on a Kaupapa Māori research study and aimed to include Māori as participants along with others in this new study controlled by non-Māori research. The only mention of Māori in the substantive research proposal was in the background with a brief reference to the prior study, the inequities for Māori in the area of research, and in the responsiveness to Māori section. The researchers claimed this was a Māori-centered study because Māori researchers were involved and some of the participants would be Māori. Nonetheless, the control of the research was under the guises of researchers who were not Māori</p> <p>The advisory group challenged this was a Māori-centered study and wanted the anomaly to be resolved. They claimed that the focus was deficit-based rather than strengths-based, the measures were focused on negative behaviors and lacked validation with Māori. Although they acknowledged that there some attempts were made to include Māori cultural values and seek cultural advice, its implementation did not flow through to the research proposed presented to the group</p>	<p>Erroneously thinking that because the research was based on a previous kaupapa Māori study and that Māori would be involved as researchers and participants, it was Māori-centered</p> <p>The deficit-based approach adopted did not meet the needs and aspirations of the advisory group</p> <p>The absence of a by, with, and for Māori approach – that is, not Māori initiated, inadequate collaboration with Māori, and the participant make-up did not reflect a Māori participant group, but rather a mixture of ethnic and research backgrounds</p>	<p>Whakapiki tangata (Enablement)</p> <p>Māori researchers leading the prior study would be the lead investigators for this study</p> <p>Māori would be the significant researchers and participants</p> <p>Establishing respectful relationships with relevant Māori whānau (extended family), hapū (sub-tribe), iwi (tribe) and communities should underpin the research</p> <p>Whakatuia (Integration)</p> <p>Throughout the proposal, there would be evidence of Māori cultural processes and practices informing the research design, particularly for the engagement, data collection, data analysis, and dissemination and translation of the research findings</p> <p>Culturally appropriate and validated measures would be used in the research</p> <p>Ethical considerations should include culturally based ethics together with mainstream ethical requirements</p> <p>Mana Māori (Control)</p> <p>The advisory group would have been involved early in the planning stages of the research so the aspirations and needs of Māori would be met in the current study</p> <p>The research outcomes must be beneficial for improving the well-being of Māori and reducing inequities within the area of study</p>

5 Culturally Responsive and Safe Research

Ko tau hikoi i runga i ōku whāriki

Ko tau noho i tōku whare

E huakina ai tōku tātau tōku matapihi

Your steps on my whariki (mat), your respect for my home, open my doors and windows

This whakataukī (traditional proverb) outlines the importance of culturally responsive and safe research and reinforces the importance of respectful practice. The research interface is a space to establish and develop culturally responsive and safe research practices. Culturally responsive and safe research refers to the researchers' intentions to, and processes of, creating a research environment founded on collaboration with and the inclusion of those people belonging to "vulnerable" groups to ensure their cultural values, beliefs, and practices are not only recognized and respected but are integrated into all facets of the research (Wilson and Neville 2009). This collaboration and inclusion ideally begins from the inception of a research idea to the dissemination and translation of the research findings. Ideally, the research team should include researchers who belong to a "vulnerable" group(s) and informed by an advisory group comprising cultural advisors and community members. Cunningham (2000) provides a framework for researchers to identify the focus of their research with Māori:

- Research not involving Māori – where Māori are not involved. Having said this, consideration should be given to the research's potential benefits for Māori (see, for example, Hudson et al. 2010)
- Research that may include Māori – whereby participants may be Māori but the focus of the study is not specifically Māori focused.
- Māori-centered research – Māori are major participants and researchers, and the data are analyzed using a Māori lens, but the research is situated within a "mainstream" institution.
- Kaupapa Māori research – research by Māori, with Māori, and for Māori, reflected in the catchphrase "nothing about us, without us."

Hudson et al. (2010) outlines the expectations for three levels of practice – that is, research without Māori as a focus, Māori-centered research and Kaupapa Māori Research. Fundamental to creating culturally responsive and safe research spaces is the engagement and formation of relationships between researchers and those being researched. For indigenous people, engagement and relationships are cultural cornerstones which do not alter in the presence of research.

6 A Framework for Culturally Safe Research

Culturally safe research is located within the context of Te Tiriti o Waitangi/the Treaty of Waitangi (Fig. 2). Whether research is culturally safe must be decided by those groups of people being researched (Wilson and Neville 2009). Wilson and Neville (2009) claim that culturally safe research:

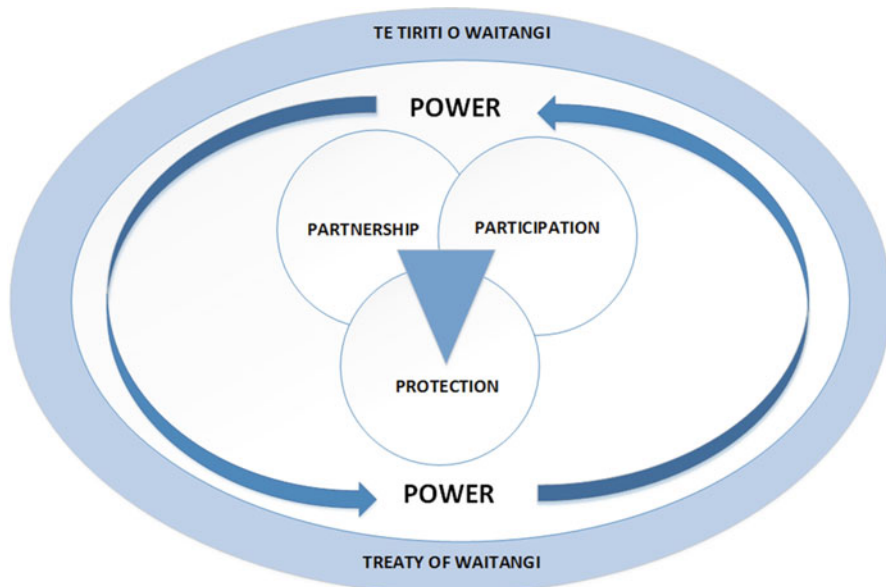


Fig. 2 The four Ps of culturally safe research

...begins from the inception of a research idea when relationships are established with those who belong to the group being researched, and extends to the dissemination of the findings. It is about research participants feeling included, respected, and that they can trust the researchers and what they will do with the information shared about them. (p. 72)

The principles of partnership, participation, and protection, sometimes referred to as the 3Ps, are commonly used to apply the Treaty of Waitangi to research practice, although a fourth 'P' is also presented here – that is, the principle of power which researchers can choose to either use cautiously and responsibly or misuse (Wilson and Neville 2009).

Partnership involves researchers establishing meaningful relationships with the appropriate Māori (tangata whenua (people of the land)/mana whenua (local iwi for whom researchers are intending to research), whānau, hapū, iwi, or Māori communities). Building meaningful and enduring relationships is crucial to the success of the research, and importantly to the credibility of the researchers within Māori communities and the integrity of the research (Smith 2012; Wilson and Neville 2009). Establishing these relationships requires identifying the right people to connect with and ideally meeting face to face. These relationships are not one-off or sporadic interactions, but instead they last throughout, and sometimes beyond, the life of the research. Importantly, established relationships are essential to access and engage participants belonging to vulnerable groups. They know who researchers need to connect with, and who possess the community credibility necessary to involve those people who are suspicious and distrust researchers. Moreover, participating in research is not necessarily a priority for many who are vulnerable, especially when many face daily life challenges.

Māori have culturally-based ethical principles to guide research being undertaken with Māori (Hudson et al. 2010). These ethical principles reflect traditional Māori values associated with tika (being correct and appropriate), pono (being honest and having integrity), aroha (having unconditional respect), manaaki (taking care of others), whānau (collective extended family), and whanaungatanga (establishing relationships and connections), for instance (Mead 2003). Using these ethical principles, in addition to institutional ethical requirements, ensures research participants and researchers alike are kept culturally safe. Therefore, being respectful of the people that you interact with as well as the relevant cultural processes and practices should underpin all actions.

Researchers unfamiliar with Māori tikanga (cultural processes) should undertake early consultation about obtaining the necessary cultural advice and guidance needed to be followed to keep the research team and the research culturally safe. It is crucial that, where possible, researchers arrange to meet face to face with Māori – the known face is important within Māori communities for engagement and data collection. Community-based research assistants who are known within the community can be helpful. It is crucial when engaging with Māori whānau, hapū, iwi, and communities, researchers observe how things are done, observe and listen to what is being said before speaking, acting with humility at all times, and building into research proposals manaakitanga (taking care of research participants) (see Box 3). This may mean that providing kai (food) when going to meetings or interviews as part of the process and offering koha to participants to acknowledge and value participants' contributions and time. It is useful to note that research would not get done without participants' input – being seen to look after and care for participants is noted by Māori, and respected when it is carried out.

Box 3 Ethical Research Values

Values		Application in research
Aroha ki te tangata	Respect people at all times	Always approach Māori participants and people with the utmost respect by establishing mutually beneficial relationships with Māori cultural advisors and act on their advice and guidance
He kanohi kitea	The known face	Researchers who are known to Māori communities and who are respected and seen as credible are more likely to successfully recruit research participants. If researchers are unknown in the community, they then should have people as co-researchers who are known on the research team is essential
Titiro, whakarongo, kōrero	Look, listen then speak	Humility is highly valued in Māori culture, therefore, it is important to observe and listen before speaking. Researchers should avoid assuming they are “the experts” and remember everyone brings expertise to the research partnership

(continued)

Box 3 (continued)

Values		Application in research
Manaaki ki te tangata	Sharing, hosting, and being generous	Taking care of your participants is crucial. Providing kai (food) at meetings or interviews is one way of conveying researchers' understanding of cultural processes and the role of kai and their commitment to looking after them. Also the concept of reciprocity is important, therefore, koha (gifts) are important recognition and the valuing of the time and important knowledge gathered from people for the research
Kia tūpato	Be cautious	To avoid breaching tikanga (cultural processes), it is important to be both politically astute and aware
Kaua e takahia te mana o te tangata	Do not trample on the mana of the people	Upholding the mana of people, no matter how different they are from the researchers, is important. People are born with and acquire mana over their life – it can be diminished by researchers not valuing people and respecting cultural traditions, for instance
Kaua e māhaki	Don't parade your knowledge	As mentioned earlier, researchers having a sense of humility is important – remembering that the people are “experts” on their life and realities they must be treated accordingly and thus respected at all times. Researchers conveying a sense of self-importance and expertise can show they lack the necessary humility to work effectively with the people

Adapted from (Smith [1999](#))

Researchers need to be mindful and respectful of both individual and collective rights (which may mean, for example, that iwi or hapū consent and support is required for the research to occur in an area in addition to individual participants' consent). It is also important for researchers to recognize the diversity in cultural identity and connection amongst contemporary Māori (as they were prior to colonization). They range from those with strong cultural identities and connections to those who know they are Māori but who are disconnected from their cultural lands and traditions and without the necessary connections to rectify this. The New Zealand Census 2013 shows there are 70,000 more people who claim Māori ancestry than those who identify ethnically as Māori (Statistics New Zealand [2013](#)). This diversity needs to be considered when planning research, and caution must be taken, assuming all participants are culturally connected (know where they are from and who they are) and can speak te reo Māori, for instance.

Box 4 Examples of Ethical Relationship Building

Examples of practice lacking cultural responsiveness	Culturally responsive engagement
<p>Initiating engagement: researchers planned to undertake a study requiring regular input and feedback from a variety of key informants. Because of Māori over-representation in the area of study, it was decided to include Māori key informants. A list of names was compiled and in due course people were contacted by email. A potential Māori key informant expressed dismay and concern about the process used. The research team was distressed by this negative response</p>	<p>Planning to develop research relationships requires researchers to commit to organizing with the appropriate and relevant Māori (be it whānau, hapū, iwi, or community) to initially meet kanohi ki te kanohi (face to face) to discuss planned research and seek their input. Writing letters or sending emails at the beginning is not a culturally appropriate form of engagement. If it is not practical to physically meet with the appropriate people or group, then at a minimum a phone conversation should be had and an explanation provided conveying the researchers' awareness of the preferable need to meet and discuss the request. In similar circumstances, researchers are advised to offer an apology for the process they used to preserve possible future relationships and credibility</p>
<p>Consultation: researchers met with local Māori iwi to discuss their planned research and to obtain evidence of their consultation process required by the funding agency. When they arrived the researchers conveyed an attitude of paternalism and presented themselves as "experts" that Māori should be thankful to have interested. This curtailed the meeting before the researchers expected – they wondered what had happened</p>	<p>A key value for Māori is humility – displaying being knowledgeable about everything and as the experts does not build the confidence in Māori that participants will be looked after during the research or that researchers will listen to what they have to say. Therefore, Māori in this community have decided not to proceed further with the conversation and are highly unlikely to participate in the research</p>
<p>Participation in the research design and process: the principal investigator decided to have preliminary discussions with a local kaumātua (elder) about a research idea. The meeting began with whakawhanaungatanga (connecting by sharing where they were from and who they were). Following this the researcher shared what was intended and invited feedback from the kaumātua. The kaumātua thought the research would be of value but suggested that for it to be of real value to their community, he suggested they slightly altered aspects of what they were planning. He said if these changes were made, their community would support the research and help with the participant recruitment</p>	<p>This example demonstrates the researcher's willingness to engage with the Māori community, establish key relationships, and involve them in the early planning stages of the research. In addition to this, the researcher showed a willingness to respect an important cultural practice – that is, making connections and establishing relationships. This is an illustration of partnership, protection and protection in action, and a willingness of the researcher to use power in a positive and appropriate manner</p>

Participation requires Māori involvement in the entire research process, from the beginning of a research idea to the dissemination and translation of findings for their application. This then optimizes research aligning to the aspirations and needs of vulnerable groups, such as Māori, the outcomes will be meaningful and useful, and Māori are involved in the interpretation of the findings. In addition to consultation and collaboration activities, Māori should also be significant research team members in order to build research capacity and capability.

Protection requires thoughtfulness about how Māori cultural beliefs, values, and practices are identified and understood so that they can be respected and protected during the research process. Furthermore, the benefits researchers reap from undertaking research in the forms of employment, gaining qualifications, the kudos arising from research, and the presentation and publication of the findings in various forums are obvious. It is equally important research is beneficial for those being researched. Thus, researchers need to be clear and transparent about what the actual and potential benefits are for participants and the wider community.

Power is another area which researchers must be mindful about as they possess power that can either be used to benefit participants or be misused. The power researchers wield comes in the form of the decisions they make about planning and designing the research, such as deciding to establish relationships with the appropriate people or to short circuit the process by coercing people who are not necessarily the right people. Moreover, the process for interpreting and reporting research findings and the worldview used to do this are important decisions that can result in beneficial or less than beneficial outcomes. How power impacts the research and the scope for sharing it must be considered by researchers, and ideally is something that is discussed early in the research with Māori.

Using partnership, participation, protection, and power as a framework guides culturally responsive and safe research practice that is situated within the context of Te Tiriti o Waitangi. Such an approach goes someway to promoting research that “gets the story right.”

7 Conclusion and Future Directions

The notion of vulnerability is a somewhat contested notion that can imply some form of deficit for those being assigned such a label. In this chapter, vulnerability has been framed as those groups of people being faced with persistent inequities and being subjected to discriminatory research practices that overlook not only their culture but also their everyday realities. High-quality research outcomes are essential if they are to usefully contribute to eliminating inequities and their associated burdens, and importantly achieve health equity. Getting the story right is an essential ingredient for transformative research that makes a difference for indigenous peoples like Māori. Therefore, inclusion of indigenous ways of being that privilege a worldview based on whakapapa (genealogy) which is holistic, spiritual, relational, and ecological in nature is without question. Culturally relevant approaches to research facilitates understanding the sociocultural contexts within which inequities and disadvantage occur, and how these impact on Māori access to social and health

services and the achievement of equity. In order to get their story right requires the selection of approaches that accurately reflect the people's voice along with their historical and contemporary realities and that focuses on generating transformational Māori outcomes. Discontent and frustration with research extends to the research methodologies and approaches used to research them as a people (Walker et al. 2006). Kaupapa Māori research, defined as research "by Māori, for Māori, with Māori" (Smith 2012), legitimizes and validates Māori epistemology, ontology, and axiology. Kaupapa Māori Research and Māori-centered research both offer Māori the necessary agency to safeguard the research process and generate knowledge that is valid and useful to Māori Cram (2014).

Culturally responsive and safe research is essential – this can be achieved in part by the inclusion of indigenous researchers and indigenous research methodologies. Nevertheless, this alone is insufficient as research will continue to be done on indigenous peoples by nonindigenous researchers. Culturally responsive and safe research requires researchers to not only consider their personal cultural locations and the imposition this can have on the quality of the research and the methodologies selected but also consider the unconscious biases they may bring to their research practice. It also calls for researchers to make sure that they engage with communities in a culturally appropriate and respectful manner. This requires establishing relationships and involving indigenous peoples early in the research process through to its completion. Within the context of Te Tiriti o Waitangi, the framework of partnership, participation, protection, and power can usefully be used to guide researchers. Culturally responsive and safe indigenous research should primarily be focused on respectful and fruitful research that aims to achieve equity and improve social and health outcomes.

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Using an Indigenist Framework for Decolonizing Health Promotion Research

89

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Contents

1	Introduction	1544
2	Maiwah as Place: Place as Ontology	1546
3	Indigenist Research	1548
3.1	Resistance as Its Emancipatory Imperative	1549
3.2	Political Integrity	1552

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3.3 Privileging Indigenous Voices	1556
4 Conclusion and Future Directions	1559
References	1560

Abstract

This chapter provides a critical reflection on an ethnographic approach led by a non-Indigenous researcher in partnership with an Indigenous community-controlled health organization, and a team of Indigenous and non-Indigenous supervisors, advisors, critical friends, and mentors. The chapter explores the way the three interrelated principles of Indigenist research informed the study, as a critical reflection of the methodology's achievement of a decolonizing research agenda. The flow of Maiwah (the Brisbane River in Australia) provides a metaphor for the chapter's diverse authorship. Maiwah's tributaries, inlets, and banks represent author voices at different points while the one River flowing represents coming together to form a broader collective story of the research that still respects the authors' individual positioning. Maiwah's flow also signifies the dialogical approach of the research – "tricky ground" (Smith 2005) for non-Indigenous researchers seeking to privilege Indigenous voices while remaining accountable to their own White privilege, particularly given that at its most basic level, research requires the "extraction of ideas" from participants. Yet, the flow of Maiwah also shows us the possibilities of research, where in this case, researcher and participants together cocreated new knowledge in support of their agendas. This process enabled both research outcomes and increased research capacity and confidence in the host agency and researcher. On this account, decolonizing research is perhaps more about relationship and devolving control over the process than it is about particular methods, and the respectful negotiation of epistemological meanings and representation of particular knowledges that can result.

Keywords

Indigenist research · Decolonizing methodologies · Health promotion · Indigenous Australians · Non-Indigenous Australians

1 Introduction

Non-Indigenous people largely control health research in Australia. Health research has, therefore, either ignored the presence and needs of Indigenous Australians or has maintained a colonial stance, conducting research on Indigenous people rather than with Indigenous people. While there has been a growth in recognition of this colonial dynamic within health research and a resultant call for a decolonizing of the space (Sherwood and Edwards 2006; Fredericks and Anderson 2013), guidance on how to unfold a postcolonial research practice remains limited. Using a case study of a "decolonizing" health promotion research project conducted by a non-Indigenous researcher in partnership with an Indigenous community-controlled organization,

under the supervision of Indigenous and non-Indigenous scholars, this chapter provides a critical reflection of the learning gained from this experience and examples of strategies that may assist others in the decolonizing endeavor.

The argument for improved research processes and ethical frameworks to redress Indigenous health inequality is already well established (Thomas et al. 2014). In Australia, the National Health and Medical Research Council (NHMRC 2003) guidelines emphasize community-driven and community-controlled participatory approaches, while elsewhere the importance of research translation and collaboration has been emphasized (Laycock et al. 2011). Positive change has been taking place in Indigenous research, with governments listening to Indigenous Australians (Fredericks et al. 2011), who are now actively engaged in determining the details of research, including the conditions under which it should take place (Fredericks 2007). Despite this, “Aboriginalism” continues in health research, characterized below:

...the story about Aborigines told by whites using only white people’s imaginations. Aboriginal voices do not contribute to this story, so in Aboriginalism, the Aborigines always become what the white man imagines them to be. (Walton and Christie 1994, p. 82; cited in Rigney 2006, p. 34)

Decolonization requires a centering of the concerns and worldviews of the colonized “other” (Chilisa 2012; Smith 2012). To do so requires having a critical understanding of the underlying assumptions, motivations, and values informing research practice (Smith 2012). Thus, the decolonization of research involves research reform according to Indigenous peoples’ aspirations of empowerment and self-determination (Bainbridge et al. 2015). It involves a process of questioning how the disciplines – in this case, health promotion – “others” Indigenous people by continuing to legitimize the “positioned superiority of Western knowledge” (Chilisa 2012, p. 14; see also Said 1993; see also ► Chap. 15, “Indigenist and Decolonizing Research Methodology,” ► 87, “Kaupapa Māori Health Research,” ► Chap. 88, “Culturally Safe Research with Vulnerable Populations (Māori),” ► Chap. 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,” and ► 97, “Indigenous Statistics”).

Decolonization is a question for both Indigenous and non-Indigenous people. Decolonizing research involves liberating the “captive minds” of both the colonized and the colonizer from oppressive conditions that silence and marginalize the voices of the colonized (Chilisa 2012, p. 14). It requires a consensus of effort but also recognition of the different voices involved. To provide some practical insight into how this can be approached, this chapter examines a case study of a health promotion research project led by a non-Indigenous researcher in partnership with an Indigenous community-controlled health organization, and a team of Indigenous and non-Indigenous supervisors, advisors, critical friends, and mentors. The reflection provided here explores the decolonizing agenda in health promotion research by drawing on the three principles of Indigenist research (Rigney 1999; see also ► Chap. 15, “Indigenist and Decolonizing Research Methodology”) using the metaphor of Maiwah, the Brisbane River in Australia.

2 Maiwah as Place: Place as Ontology

A starting point for writing about decolonizing research is to introduce how the lives and worldviews of the authors are intertwined. To do this, we have deliberately chosen to use a metaphor which privileges Indigenous ways of knowing, to introduce each author's position in relation to the Place of this study, the flowing Maiwah. Maiwah meanders through South East Queensland (SEQ), the Place upon which the Institute for Urban Indigenous Health (IUIH) operates (Box 1). IUIH is where the study that has informed this chapter took place. Karen McPhail-Bell was a PhD candidate supervised by Mark Brough, Chelsea Bond, and Bronwyn Fredericks, while Alison Nelson and Ian Lacey were IUIH staff involved in the PhD study. Bronwyn, Chelsea, and Ian identify as Indigenous Australians, while Karen, Mark, and Alison identify as non-Indigenous Australians.

Box 1 Overview of IUIH

The research site of this study was the Deadly Choices team within IUIH, based in Brisbane, the capital city of the state of Queensland in Australia. In 2009, the four community-controlled health services in SEQ established IUIH, with the leadership and support of the Queensland Aboriginal and Islander Health Council. IUIH's establishment was a strategic response by these bodies to the growth and geographic dispersion of Indigenous populations within SEQ, and their associated under-servicing (IUIH 2011). IUIH maintains that its model for operation is the only one of its kind in urban Australia, providing a way for Indigenous communities to have a voice in improving health outcomes in an urban setting. IUIH has worked with SEQ AMSs to drastically increase the number of clinics and facilities available to Indigenous Australians in the SEQ region. Since 2009, these clinics have grown from 5 to 18, with more planned, and IUIH has expanded from six staff members in 2009 to over 430 employees in 2016 across IUIH and the clinics it established.

IUIH's core business involves coordination and integration of comprehensive primary health care across SEQ, including clinical care, health promotion, and preventative health, all of which work together to achieve its vision of equitable health outcomes for urban Indigenous Australians. IUIH established Deadly Choices in 2010 as part of its response to rising prevalence of chronic disease in Indigenous communities, funded primarily through the Australian Government Closing the Gap initiative. Deadly Choices is IUIH's key health promotion initiative.

The flow of Maiwah provides a metaphor for this chapter's diverse authorship. Maiwah's tributaries, inlets, and banks represent our voices at different points in this chapter (and in the research project), while the one River flowing represents our coming together to form a broader collective story of the research that still respects our individual positioning. As the main watercourse and water source for Brisbane,

Maiwah begins in the Brisbane Range approximately 140 km from central Brisbane. It begins high from water falling from Mount Langley; quietly, gently Maiwah moves downwards, gathering more waters as it travels, growing, and taking different forms and objects on the journey. Maiwah connects with the Stanley River and runs into Lake Wivenhoe, meandering eastward as “a serpentine river which follows you as you drive through the inner suburbs of Brisbane” (Megarritty 2015, p. 101). Maiwah winds and curves, smoothing the rocks it covers, depositing soil, playing with sticks; it widens and deepens, strengthens as a force, as it edges closer to its end. Its character is established, dictating its own path through the Brisbane Maiwah valley and the heart of the city of Brisbane. Maiwah eventually runs into Quandamooka (Moreton Bay) where Stradbroke Island sits in Maiwah’s mouth. At this river mouth, salt water and winds wash sand through the channels of Quandamooka into the catchment area of the Brisbane River (Martin 2003). Two bodies of water meet and meld. There are points of difference and points of connectivity, and an energy in the relationship of the waters as they come together.

As Maiwah journeys and connects with land, water, animals, and so on, flowing with various eddies and swirls along its path, so too did this research begin, grow, and connect with people and communities. As is Maiwah’s way, this research process built relationships and a project that created a new, shared knowledge. Research always requires negotiation with different stakeholders and their needs. In the case of this chapter, we bring different disciplinary and cultural knowledges, experiences, and viewpoints. Like Maiwah’s tributaries, each of us is connected to the other in some way; mutual respect and trust are key as each negotiates the ever-present tensions in trying to engage in decolonizing research. Thus, this chapter is both an expression of different knowledges and viewpoints as well as a demonstration of common themes. Like Maiwah’s flowing waters, there were times when we encountered obstacles that required navigating, and this too is part of decolonizing research, which makes the end product broader and deeper (see Box 2).

Box 2 Mark Reflects on His Position as Principal Supervisor in the PhD Research Project

Movement toward postcolonial research requires careful reflection of the “self-other” and an associated questioning of the colonial imaginations of expert/instructor. Here, the neat binary of researcher/researched needs attention too, since the dialogue of this project also involved a team of Indigenous and non-Indigenous advisors as well as interaction with an Indigenous organization which whilst predominantly made up of Indigenous workers, included non-Indigenous workers as well. Thus, the challenge of a postcolonial dialogue criss-crosses multiple overlapping spaces of academia and community. As a non-Indigenous academic in the role of “principal supervisor” a powerful White institutional framework surrounded my own position privileging my authority. I have observed a great deal of “White fragility” (DiAngelo 2011)

(continued)

Box 2 (continued)

within academia when confronted with questions of racism and the “other,” hence non-Indigenous researchers attempting to operate cross-culturally within a postcolonial paradigm must be prepared to question both their own fragilities as well the disciplinary and institutional fragilities surrounding them. Indigenous authority is quickly dismantled by White fragility within the dialogic encounter. Maiwah flows best when all tributaries are open and this requires awareness of the ways in which those tributaries can become blocked.

By positioning the research as the flow of Maiwah, we are seeking to engage the principles of Indigenist research (Rigney 1999, 2006) to demonstrate an alternative epistemology and ontology to that more commonly seen in Western research and textbooks. Mary Graham (2006, p. 6) talks about the importance of Place in knowledge for the way it explains “how and why something comes into the world” and provides a balance and rebalance when used like an “ontological compass.” Attention to ontology is important for Indigenous and non-Indigenous researchers alike to develop an awareness and sense of self, of belonging and the responsibilities that belonging brings, including how we relate to ourselves and others (Martin 2003).

3 Indigenist Research

Following Maiwah, different authors speak at different times in this chapter. At some points, boxes highlight the voice of a particular author. At other times, the voice of particular authors leads as they write about specific aspects of the research, as tributaries that make the whole river. In this section, the way the three interrelated principles of Indigenist research informed the study is discussed (Rigney 1999). These are:

- (a) Resistance as its emancipatory imperative
- (b) Political integrity
- (c) Privileging Indigenous voices

Together, these principles function to clarify what is and is not meant by Indigenist research; they provide a strategy for research rather than a process (Foley 2003). We recognize that the explicit criteria of Indigenism are the Indigenous identity and colonizing experience of the writer (Rigney 2006). We also recognize that collaboration and participation models involving non-Indigenous researchers in Indigenist research, undertaken with examination of relationships (among the researcher and researched, to knowledge and to self), can lead to greater agency of Indigenous people and thus enact an Indigenist approach (Smith 2001, cited in Martin 2008; see also ► Chaps. 15, “Indigenist and Decolonizing Research

Methodology,” ► 87, “Kaupapa Māori Health Research,” ► 88, “Culturally Safe Research with Vulnerable Populations (Māori),” ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,” and ► 97, “Indigenous Statistics”). In other words, when based upon self-reflexivity and dialogical characteristics, different types of relationships in collaborations can be meaningful, useful, and powerful, and achieve an Indigenist research agenda (Martin 2008). As an example, the genesis of this research case study involved a discussion between Karen and Bronwyn regarding the prospect of Karen undertaking a PhD in Indigenous health. Karen shared her caution in light of the negative and harmful history of Eurocentric research and practice. Bronwyn responded in a way that for Karen presented an opening that saw the research project beginning 2 years later (McPhail-Bell 2015, p. 8) (see Box 3).

Box 3 Bronwyn Emailed Karen Regarding Her Consideration and Caution to Do a PhD in Indigenous Health

... we need good people working with us, not around us and over us... if you do it well then it helps us. If you work with us it helps us. If you look at issues that Aboriginal and Torres Strait Islander people want you to look at then it helps us... To do nothing also maintains the inequities! ... this is what I get upset at some folks for, like if they really wanted to address inequities in Australia they would put a lot more effort into Indigenous health, Indigenous housing, Indigenous employment, Indigenous education etc... and into their own and other peoples relationships with Indigenous peoples in this country... to leave alone leaves the issues alone and unaddressed... Problem is too many people act in this way and then it doesn't get picked up... and Aboriginal people are left to do it on our own, the sickest are left to do, the poorest are left to do it, the most disadvantaged are left to struggle once again. So go for it Karen, it won't be easy but it will be worth it!!

Following Maiwah's path of connecting and flowing, this section provides a reflection of how this PhD study satisfied the principles of Indigenist research, to contribute to dialogue regarding the partnership of Indigenous and non-Indigenous researchers and practitioners in Indigenist research.

3.1 Resistance as Its Emancipatory Imperative

The first principle of Indigenist research, resistance as its emancipatory imperative, is explicitly concerned with liberation from colonial domination (both in research and society) (Rigney 2006). This principle positions Indigenist research as part of Indigenous peoples' struggle for self-determination. Maiwah's history of flooding shows us the power of resistance in order to travel new territory and bring change over time. Brisbane is built on a flood plain, where flooding is periodic

(van den Honert and McAneney 2011). The 2011 Brisbane floods saw heavy, continuous rainfall into the Wivenhoe and Somerset Dams and along the path of Maiwah. When water was released from the dam, Maiwah burst forth, resisting the chartered parameters of the dams, flooding 18,000 properties in metropolitan Brisbane (van den Honert and McAneney 2011). Maiwah's flooding and change over time is like the continued Indigenous resistance to the ongoing colonial practices and attitudes of many non-Indigenous people, including health professionals (Bond et al. 2012; Fredericks et al. 2012; McPhail-Bell et al. 2015). This resistance is about change for the emancipation of Indigenous people. In the research example drawn on for this chapter, there were several ways that resistance was enacted as an emancipatory tool. These included: development of the research question, framing the research outside "typical" health promotion approaches to research, strengths-based orientation, and shared control over the research process and outcomes.

As this research demonstrated, while Indigenous research can be a tool of colonization, it can also be a tool to counter ongoing forms of Indigenous dispossession (Martin 2008). To do this, Indigenist research focuses upon the survival and celebration of Indigenous people's resistance to racist oppression, and to cease continuation of oppression against Indigenous people (Rigney 1999; Foley 2003). An example of this can be found in this study's research question, which the authors argue was emancipatory in nature. The nature of the research question was opened to ensure that the PhD research was grounded in the everyday lives of Indigenous people. The research question served to achieve the study's aim to contribute to the decolonization of health promotion practice and accordingly, to recognize Indigenous knowledge, skills, and experience in health promotion. Such an aim was a direct rejection of health promotion's tendency to position Indigenous people as victims requiring outside intervention, and as lacking knowledge and expertise in health promotion. It was also a rejection of health promotion's ahistorical self-positioning regarding colonization and its role in that (McPhail-Bell et al. 2015). To achieve this aim, the research enquired into the daily practice of a cross-section of Indigenous and non-Indigenous health promotion practitioners, in an urban setting of Indigenous-led health promotion. The resulting research question was: *How do health promotion practitioners in an urban Indigenous setting make sense of and navigate the tensions inherent to health promotion in daily practice?*

Note that the research question opened with the presumption that there was something to learn from Indigenous-led health promotion practice for all of health promotion. The presumption of Indigenous expertise also informed a review of the health promotion literature from a decolonizing lens. Researchers are responsible for examining the historical basis of the methodologies and disciplines involved in their research to achieve a decolonizing agenda (Nakata 2007). In this study, the historical basis for health promotion and its relationship to Indigenous peoples was critiqued, including whether it was modeled on learning from Indigenous peoples as equals (McPhail-Bell et al. 2013). Likewise, the basis of the selected methodology (critical ethnography) was reviewed, including the role of non-Indigenous women in its use and in Australia's relations to Indigenous peoples more broadly, given it was a non-Indigenous woman leading the research.

There is an awkward tension for non-Indigenous researchers to negotiate in their efforts to apply decolonizing approaches to research, not only because Indigenist research requires that Indigenous researchers are privileged (Rigney 2006). Nonetheless, this is far from reason to not be involved. Rather, non-Indigenous researchers must come to the research in opposition to the colonial nature of “Aboriginalism” and the unequal power dynamics between Indigenous and non-Indigenous people (Rigney 2006). Thus, as the “research tool” (Madden 2010) it was essential that the lead researcher remain critically reflexive of their own position in the research, given its influence on the research approach and interpretation (see Box 4).

Box 4 Karen’s Reflection on Identifying Her Position and Assumptions in the Research

I began the research with particular assumptions, as every researcher does (identified or not). My standpoint is grounded in knowledges of different realities to those of Indigenous people (Moreton-Robinson 2000), so I spent time to articulate my ways of being, doing and knowing (Martin 2003; Moreton-Robinson and Walter 2010). This is because as non-Indigenous researchers, we have a responsibility to investigate our own subjectivities and our society, political and cultural positioning when engaging with Indigenous peoples (Fredericks et al. 2014).

I view Indigenous people not as “other” or “non-other,” but as a people whose subject position is “fixed in its inalienable relation to land” (Moreton-Robinson 2003, p. 31). This viewpoint means that I view myself as being in relation to Indigenous sovereignty, which helps me to better understand my complicity with benevolent practices that normalize Whiteness and the construction of people as passive objects (Riggs 2004, p. 8). It also means that I began this study with the assumption that Indigenous-led health promotion carries strengths from which mainstream health promotion could learn. There was no one driver of this assumption but a major reason was my belief in the power of self-determination for people’s health. This belief was against a backdrop of mainstream health system failure to effectively act to address poor Indigenous health, and to genuinely partner with Indigenous peoples and communities. My assumption of strength and its associated analysis could allow for possibilities to move beyond colonial control, towards a place of mutual respect (Said 1978).

To be emancipatory, the research required a theoretical framework to guide the work to be process driven, as well as outcome oriented (Rigney 2001). Such a framework supported the research project and its aim by drawing on a decolonizing approach. In practice, this translated to being strengths-based and guided by theoretical tools that enabled the research to move towards decolonizing epistemologies and identify the manifestation of racism in research practices and knowledge production (Rigney 1999). These theoretical tools were: critical race theory and

postcolonialism to position the lead researcher, and health promotion as a discipline and practice; and the cultural interface, to move beyond the constraint of a pre-defined and reactive anticolonial agenda (Nakata 2007). As a whole, the framework aligned with a decolonized approach by critiquing the dominance of a Euro-Western paradigm and inquiring into how knowledges converge and evolve through their daily enactment. Together, these tools enabled the decolonizing approach to give voice to the researched and move from a deficit-orientation (Smith 2012), along with expansion of assumptions that underpin existing health promotion theory and practice.

3.2 Political Integrity

Political integrity, the second principle of Indigenist research, highlights the importance of Indigenous ways of being and knowing based on Indigenous philosophies, cultural values, and beliefs (Rigney 2006). This principle is reflected in the use of Maiwah as a tool for describing the ways in which we have merged our different knowledges and experiences to produce this chapter and the research underpinning it, rather than drawing on a more “standard” Western knowledge system to describe this work. The research presented throughout this chapter also highlights the processes through which a non-Indigenous researcher can maintain this political integrity when working in partnership with Indigenous participants and supervisors.

Political integrity in Indigenist research requires that there is a social link between research and the political struggle of Indigenous communities (Rigney 1999). It emphasizes the need for Indigenous communities to build their own capacity mechanisms to gain the benefits of research (Rigney 2006). However, while Rigney (2006) argues that political integrity necessitates Indigenous researchers conduct the research, he also acknowledges that non-Indigenous researchers can draw upon these principles if upholding the struggle for genuine self-determination of Indigenous people. The methodologies chosen thus also need to enable a countering of racism and privileging of Indigenous knowledges and experiences for Indigenous emancipation (Rigney 1999).

Fundamental to political integrity in Indigenist research is the premise that the researcher must negotiate with the participants at all levels of the research design, including data collection, analysis, and reporting of findings (Rigney 1999). To do this, there was a need for the researcher to be vigilant in learning to operate in decolonizing ways through significant self-reflection, listening, and learning. Relationality formed the basis of the research methodology; it is ethical to do so and part of a decolonizing approach (Martin 2008; NHMRC 2003; Nicholls 2009). This included spending approximately 12 months building relationships and informing potential participants about the research, including what a PhD would involve. In practical terms, this meant volunteering, attending team meetings and other work activities, and finding ways to support the work of the team being researched (see Box 5). It also necessitated an investment of time to learn about the priorities and needs of those involved, and embed these into the research. This

approach required an open agenda for collaborative research planning to take place, embedding the research within the team so that it could adapt to their needs and requirements as the research progressed (see Box 6). The important factor was time in “being there” with potential participants to build relationships, and collaboratively design the research (see Box 7). This is consistent with building trust and cooperation as core tenets of maintaining political integrity in Indigenist research (Rigney 2006).

Box 5 Ian Reflects on the Presence of Karen as a Researcher with Their Team

Karen was very helpful; she wasn't a researcher; she was just an extra set of hands, just helping. And when we have our community days, any extra sets of hands that we have are very helpful for the team. So most of the time, I didn't see Karen as a researcher, when she attended community days or programs or events; so, that's a positive thing. We didn't have to segregate her and say, “You can't do this task; you're a researcher.” She just jumped in and was part of the team. Once you're part of the team and everyone's helping each other out, it just flows. Karen was helping out on the days and would come back and feed back to us and we weren't even aware that she was observing us most of the time. We knew she was there to do the research but once we started the days, and she wasn't sitting back with a notepad and just doing that sort of thing, it just became easier; Karen was just there and part of the team. So, that was helpful to us and helpful to Karen.

Box 6 Alison Nelson Reflects on the Relationship-Building Phase of the Research

I think the beginning of that process was very much about relationship-building and trust. . . it was a pretty vague concept when it first started and I think that's a key thing for research in this area, or service delivery, especially if you're starting something new, is that there will be periods of time when it's really uncertain and there's a lack of clarity and it's a bit vague and a bit unclear. . . I also think that that's part of the success because I think if Karen had come to these guys and gone, “I'm going to do exactly this, this, this and this,” it probably wouldn't have worked as effectively as her saying, “I've got this idea of what I'd like to do and then let's just see how it works. I'm just going to build relationship with you and become part of the team. I don't have any agenda really at the moment, I'm just getting to know you guys.” That was then what led to the trust, and also helped inform Karen about what might be useful for her research. And I think if you go into that space with this preconceived idea, you're less likely to get that trust back from the team that you're working with. . . but Karen approached it from that trust and building relationship.

Box 7 Ian Reflects on the Initial Stages of the Research and the Way That Karen Worked with the Team

Karen was there, helping us at community events; we weren't thinking, "Oh that's Karen, she's evaluating us here." She was just there as part of the team and would come back and feed us back something about that day and we'd be like, "Oh yeah, that's right, we did do that and that was the methodology behind us doing it that way." So, that was good. It was a learning curve for me to understand fully what the research was going to be about and that probably took me a 6 month period to give me the confidence to then instil that into the team, and then be confident enough to speak up at team meetings to say, "When Karen needs something done you need to put it forward" – you know, the participant diaries and all that sort of stuff. If I didn't have the confidence in what was happening, I wouldn't have been able to give that confidence to the team. So, I think that was part of the learning curve.

The research approached decolonization of knowledge by supporting self-determining processes by Indigenous people – including by working with processes of IUIH, as an organization based upon Indigenous self-determination – and opposing colonial structures of knowledge production (Evans et al. 2014). Critical to this approach was learning about and maintaining Indigenous ideals, values, and philosophies as core to the research agenda (Rigney 2006). This meant working within a framework of an Indigenous-led and community-controlled organization and assisting the team being researched to simultaneously describe and understand their ways of knowing and doing, without predetermined theoretical or methodological constraints (see Box 7).

In practice, informal conversations, presentations, and feedback papers during fieldwork were used to inform the team about research learnings and interpretations. These were also used to inform a dialogue with participants and IUIH to ensure the research findings and interpretations reflected and respected the knowledge and experiences of participants. This approach accorded the participants the right to speak for themselves and engage in their own self-reflection in research (Rigney 2006). Regular communication about the research and PhD processes itself, including seeking permissions from participants and IUIH before including that information in public documents, was also part of working in an ethical, decolonizing way. The principle of political integrity was also enacted by supporting the team involved to develop its own practice framework and research capacity, as requested by IUIH (see Boxes 8 and 9).

Box 8 Ian Reflects on the Strengths-Based Nature of the Research

I think Karen just helping us believe that what we were doing was true to the research. We weren't doing something that wasn't of value; we weren't doing

(continued)

Box 8 (continued)

something that wasn't for the community. The research helped reinforce that we were on the right path. That was one of the biggest things for me because we weren't very good at research and evaluating programs and evaluating effectiveness in the community. We knew we had a model there that was good for the community but we didn't have any facts to reinforce that. That was one of the biggest things for us: the research helped reinforce that we were on the right path. It gave us the self-belief to go the next step with it, to say, "Righto, you've got a good model, the community's buying into it, now we got the evidence behind it – what's the next step to make it even more powerful?" It just helped reinforce that our model was working; and you need that academic validation when you're talking back to governments and others (funding providers. . . Broncos, etc).

Box 9 Ian Reflects on the Impact of the Research for Him and His Team

The team members have all really improved. Look at (team member A), (team member A's) doing an MBA now. (Team member B) has enrolled in university. (Team member C) has enquired about university. So, all this sort of stuff on the back of what has happened here in the research has been really beneficial for our team. And I think the research has also given tools: it's helped us as a team to evaluate our strengths and our weaknesses, and what plans we can put in place to minimize risks and make sure we are doing the right stuff in the community. It was really beneficial, I think, the whole experience: it instilled a real self-belief in the team. It did because like me and (team member A) personally, when we first started, we had no idea what research was but you look at us now: we're evaluating everything, we're making sure that research is tied into everything we do because it's all evidence-based, what we do. It has really instilled a real self-belief in us personally and as a team. It has helped us be who we are.

Fundamentally, to maintain political integrity, non-Indigenous researchers must support the work of Indigenous communities and their researchers (Rigney 2006). Decolonizing research might also be understood as anticolonial research, where non-Indigenous researchers work as allies with Indigenous people (Max 2005). Advocates of anticolonial research argue that it must be initiated, directed, and controlled by Indigenous people and be of direct benefit to those involved (Max 2005). The principles of ownership, control, access, and possession are self-determination applied to research (Schnarch 2004). Non-Indigenous people can work in collaborative ways with Indigenous people, which will also result in greater critical self-reflection of one's own privilege and position (Max 2005).

The Indigenist research principle of political integrity also maintains a significant tension for non-Indigenous researchers who continue to have a function in representing and speaking for the participants. In this research, while acknowledging that Karen did “speak for” the participants in her PhD thesis, there was also an effort to “speak to” in dialogue with those involved to be accountable and responsible for what was said (Spivak 1988; Alcoff 1991). Mutual respect and power sharing were enacted as further expressions of political integrity through clear acknowledgement of researcher biases implicit in Karen’s researcher standpoint. Personal stories were woven into the academic work, recognizing that narratives enable a deep understanding of what it means to be located at the cultural interface (Young 2001). Being a non-Indigenous researcher seeking to learn from Indigenous peoples is a point of contention and a matter with which all researchers must contend; this is, as Linda Smith says, “tricky ground” (Smith 2005, p. 114).

3.3 Privileging Indigenous Voices

Indigenist research focuses on the lived, historical experiences, ideas, traditions, dreams, interests, aspirations, struggles; in other words, it gives voice to Indigenous people (Rigney 1999). The way that inlets and tributaries assemble to form the flowing Maiwah provides a reminder of the importance of privileging Indigenous voices. When tributaries reach the river, they can be diluted in the larger river. Moving water is a powerful force, as is the power of hegemonic Whiteness, which works to silence Indigenous voices (Moreton-Robinson 2006). Therefore, integral to this research has been the use of different ways of privileging Indigenous voices and knowledges, including through engagement with the supervisory team (see Box 10).

Box 10 Chelsea Bond Reflects on Her Role on the Supervisory Team

Health research interest in Indigenous Australia, both in its absence and its presence has and continues to serve the colonial project. Control over the lives of Indigenous peoples is maintained through the production of knowledge that evidences Indigenous inferiority even in the most benevolent endeavours of “closing the gap” of Indigenous health inequality. The supposed relinquishment of biological notions of race has not hindered the reproduction of racial hierarchical arrangements via Indigenous deficit; socially, culturally, psychologically and intellectually. Within health research Indigenous peoples and knowledges are frequently silenced, subjugated and exploited and this rings true not just for Indigenous peoples as the subjects of study, but also for Indigenous scholars situated within investigative and supervisory teams.

Our presence and position as Indigenous scholars in and of itself does not halt the reproduction of racialized logics, and in fact Rigney (2001) notes

(continued)

Box 10 (continued)

that race continues to be fundamental to the Indigenous scholar's oppression within the research enterprise. This oppression is evidenced by the relegation of the Indigenous scholar to the role of cultural broker/mentor on supervisory or investigative teams. In this role, the Indigenous scholar is cast as a supporting actor providing auxiliary support to the "real" knowledge producers. Configuring the Indigenous scholar as the cultural steward is an effective strategy for authorizing non-Indigenous participation in and knowing of Indigenous social worlds while also maintaining colonial assumptions, which insist that "Indigenous traditions of intelligentsia equate to 'Intellectual Nullius'" (Rigney 2001, p. 4). Recognition of Indigenous intellectual sovereignty does not require the appointment of an Indigenous only cast of researchers, rather it demands a displacement of non-Indigenous peoples from their position of knowing us exclusively and absolutely. It requires a reconfiguring of research questions away from trying to find what's inherently wrong with us, to what can be learnt about us and from us. It requires an acknowledgment of and engagement with Indigenous people as thinkers, knowers and experts whether they are study participants, community stakeholders, partners, co-investigators or supervisory team members.

The silencing of Indigenous voices is evident in research epistemologies and ways of knowing in Australia, where there is little evidence of learning from Indigenous peoples (Rigney 1999). To counter this trend, this research required continued prioritization of Indigenous autonomy and control over the knowledges, languages, and cultures involved. This autonomy and control was achieved through partnership and participatory action. For example, in addition to the planning phase already described, the study design positioned participants as co-researchers, whereby using multimedia participant diaries they could determine what data the study should examine and why. It also required the lead researcher's attention to language to ensure research terminology was presented in meaningful language to participants involved (see Box 11), and that participants' language was reflected in the research dissemination (for example, in the PhD thesis). The team members involved report this process has increased their research capacity and confidence to now determine their own research priorities and agendas (see Box 8 above). Fieldwork involved an ongoing dialogue regarding the researcher's interpretation and representation, which required her to *listen*: an essential value of ethical and respectful praxis (Sherwood 2010, p. 35). That the research prioritized Indigenous control and autonomy meant that her position as White, non-Indigenous researcher and mainstream practitioner was destabilized, where IUIH and the participants carried power regarding their knowledge and their representation in the research. This destabilization is something with which non-Indigenous researchers must contend (see Box 12).

Box 11 Ian and Alison Reflect on the Way Karen Integrated Academic Language and Concepts into Her Communication with the Team

Ian: From my point of view, it was really beneficial for my team to see it from Karen's perspective. The guys do their work, day in, day out, and they didn't realize; the research was happening but they didn't understand that it was being translated in a way, the way Karen did it. I think it was really empowering for them. I think it made them realize that, "hey I am doing my job," and it gave them the strength to continue on and build on this. And I think that proved in the feedback to Karen also, in the interviews she did with them. It was a really empowering experience and as I said, the words that Karen uses in her thesis, she didn't use those words with our guys. That really helped them – it just helped them understand they are part of a research project that is on their lives, their work lives. That really empowered them to become who they are now.

Alison: That's my observation too. I saw a real shift in people's confidence. And even though Karen didn't use the same academic language, she used enough academic language in the way that she was talking that it then empowered people to know what that language meant. So, it wasn't that she was completely removing the academic from it either, she was bringing it but in a way that was accessible. That's my main observation: that increase in confidence. Ian used the word empowering, which I totally agree with, but I think it has helped the team feel confident about what research is and that they are engaged in research and they are doing it and they're confident in doing it.

Box 12 Mark Reflects Upon the Importance of Dialogue in Decolonizing Research

Methodology textbooks provide valuable guidance on how to undertake research; however, they can struggle to convey the human experience of doing research. I was very aware that any social research has this very personal edge to it and often becomes part of the supervisor–student dialogue as research proceeds, but also aware that it often remains a hidden corner in more formal written discussions of methodology. In this project, the attempt to create a decolonizing approach to research was always going to involve more than a mechanical manual of instruction, and would need ideas, processes, interpretations, and ethical judgements produced from dialogue as the research proceeded. The dialogue needed to be collaborative, equal, and respectful, but critically aware that the backdrop of Whiteness would never be conducive to this.

It was important that this research privileged Indigenous voices not just in data collection or PhD production but also in the ways in which the research was

represented and disseminated. This included negotiations with UIIH regarding their representation in the PhD thesis, including whether participants and UIIH chose to remain anonymous (as is standard practice in maintaining the confidentiality of participants) or to be named in order to highlight successful practices. There was a tension at times in navigating the needs and requirements of completing a PhD and its theoretical requirements, while simultaneously conducting research that was of value and represented UIIH in a way which “rang true” to the organization’s philosophy and practice. These discussions took time and required an ongoing reexamination of the research and its theoretical underpinnings and practices but resulted in mutual respect and understanding of each stakeholder’s position and voice. Ongoing collaboration continues in order to disseminate the research findings, which requires creative attention to privileging Indigenous voices in a range of formats and products.

This privileging of Indigenous voices also extended to the writing of this chapter. Like the tributaries forming Maiwah, we have each provided input based on our own knowledges and positions and written in a way that reflected our experiences rather than needing to conform to a particular “way” of producing an academic work. The use of the boxes throughout the chapter has illustrated one way of alerting the reader to each author’s “voice” but so too have the use of Maiwah as a metaphor and Indigenist research principles as a guiding framework.

4 Conclusion and Future Directions

As our journey with Maiwah reaches its end in Quandamooka, a place is reached where salt and fresh water mixes, where different people and knowledges mix, to create something new. Almost in a process of renewal, this story with Maiwah shares how an ethnographic approach led by a non-Indigenous PhD candidate in partnership with an Indigenous community-controlled health organization, and a team of Indigenous and non-Indigenous supervisors, advisors, critical friends, and mentors can be enacted as Indigenist research. From this journey, this chapter proposes a set of principles that may assist others in their decolonizing journey:

1. Know yourself: your assumptions; your way of being, doing, and knowing; the basis of your disciplinary training and socialization; the limitations of your knowing. Find ways to remain accountable to this.
2. Recognize Indigenous people as knowers.
3. Decolonizing research takes time and hard work. Commit to this.
4. Decolonizing research requires relationship with Indigenous peoples and communities involved, not only participants. Build the relationship early. Be accountable to this relationship after the research is completed in terms of how the research is used.

5. Collaborate with potential participants from the beginning to form research priorities, parameters, and processes based upon their strengths and priorities. Pay attention to the research question and process just as much to outcomes.
6. Know the power dynamics of the research methodology and methods you use, particularly in relation to their colonial uses, and how your positioning exacerbates those dynamics. The same applies to your examination of the literature.
7. Negotiate research governance and feedback processes that acknowledge Indigenous sovereignty and ownership of Indigenous knowledge and intellectual property. This includes agreement on expected research products and uses of those products.
8. Ensure the process and the product/s are based on reciprocity; this includes the dissemination process.

Partnership made possible the bringing together of different knowledges and expertise in this research, to accomplish more than what could be accomplished alone (Bainbridge et al. 2015). This research project is one example of how decolonizing research can take place; it is not a template for decolonizing processes. Rather, the example teaches us that decolonizing research is more about relationship and devolving control over the process than it is about particular methods, and the respectful negotiation of epistemological meanings and representation of particular knowledges that can result.

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Engaging Aboriginal People in Research: Taking a Decolonizing Gaze

90

Emma Webster, Craig Johnson, Monica Johnson, Bernie Kemp,
Valerie Smith, and Billie Townsend

Contents

1	Introduction	1564
2	Background	1565
3	Design: “Who Else Should We Be Talking To?”	1566
4	Data Collection: “We Wanted It to Have a Social Feel”	1568
5	Analysis: “All that Work for Just a Few Pages?”	1570
6	Findings: “I Have a Good Relationship with My Patients, But they Have Never Talked to Me About that Before”	1571
7	Research Impact: “How Have Aboriginal People Benefitted from the Research?”	1572
8	Applying an Active Decolonizing Gaze: Conclusion and Future Directions	1575
	8.1 Tips to Facilitate Participation of Aboriginal People in Your Research	1577
	8.2 Things We Could Have Done Better	1577
	References	1578

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1563

Abstract

A criticism of some research involving Aboriginal people is that it is not equitable in its design or application, further disadvantaging the poor and marginalized. In Australia, much research has been done on Aboriginal people, but Aboriginal people themselves have benefited little, adding to distrust between Aboriginal and non-Aboriginal people over many years. Is it possible to take “scientific” research practices and transform them into research that can be done **with** a community rather than **on** a community? How can research findings benefit Aboriginal people? This chapter shares our study of Aboriginal people’s stories of diabetes care. It is a collaborative story told by four Aboriginal Health Workers and two non-Aboriginal researchers which focuses on methodology rather than findings. We share aspects of our research which we propose values Aboriginal people and invites participation and reciprocity at design, data collection, and research translation stages. We discuss tensions which occur between the “scientific way” and the “culturally appropriate way” and describe how we resolved this. Imposing research designs and practices on Aboriginal people and communities without consideration that each community is unique has the potential to cause further harm and disempowerment. Valuing an Aboriginal way of knowing influenced all aspects of our study design and procedures. We would like to inspire others to challenge methodological norms to develop research methods with their community to allow the unique voice of their community to be heard and for this to facilitate pragmatic change leading to meaningful improvements in health.

Keywords

Aboriginal people · Australia · Participatory research · Community engagement · Social participation · Qualitative research

1 Introduction

... [C]olonisation continues today both politically and through health service provision, research and scholarship. This is because the context of causal agents that have impacted upon the health of Indigenous Australians... have been maintained through problematic constructions of Aboriginal people that were established when the concept of terra nullius was applied to this continent. If we all take up an informed and active decolonizing gaze we can shift this colonial context. It is time to make the change; the knowledge is out there, to stop blaming Indigenous Australians for their health circumstances, and to contribute to providing the very best health care, research and scholarship to the first Australians. (Sherwood 2013, p. 37)

A criticism of research in Aboriginal health is that it is invasive, inappropriate, and unnecessary and undertaken without community consultation (Aboriginal Health & Medical Research Ethics Committee 2013). In Australia, much research has been done on Aboriginal people, but Aboriginal people themselves have benefited little, adding to distrust between Aboriginal and non-Aboriginal people over many years.

Empirical research has not been able to deliver positive health benefits to Aboriginal communities as research has often focused on Western ways of knowing and doing and ignoring the power imbalance that Western research creates between subject and researcher (Prior 2007; Kendall et al. 2011). Sherwood (2013) explains problematic constructions of Aboriginal people have persisted since *terra nullius* (land belonging to no one) and urges academics to take an “active decolonizing gaze” to research and scholarship to allow Aboriginal ways of knowing to shape research design and application (see also ► Chaps. 15, “Indigenist and Decolonizing Research Methodology,” and ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research”).

This chapter shares a study of Aboriginal people’s stories of diabetes care. It is a collaborative story told by four Aboriginal Health Workers and two non-Aboriginal researchers which focuses on methodology rather than findings. The “active decolonizing gaze” was taken to the usual “scientific” research practices to transform them into research that can be done **with** a community rather than **on** a community. The chapter outlines aspects of our research which we propose value Aboriginal people and invite participation and reciprocity at design, data collection, and research translation stages. It is designed to be an intensely practical work which describes tensions which occurred between the “scientific approach” and the “culturally sensitive approach” and discussed how we resolved this.

This chapter is written for academics and practitioners who would like to challenge methodological norms to develop research methods with their community to allow the unique voice of their community to be heard. Research findings can then facilitate pragmatic change and meaningful improvements in health.

For the ease of the reader, we have described our research in the sequence one would expect in a research report. However, the stages were generally not as clearly defined and were often concurrent rather than consecutive. Tensions are highlighted where they occurred in the chronology of the research.

2 Background

Dubbo is a city in regional New South Wales with a population of 40,000 people of whom 5,000 are Aboriginal (Australian Bureau of Statistics 2011). Dubbo is part of the Wiradjuri nation. There are many Aboriginal nations in Australia and Aboriginal people from many different nations reside in Dubbo, often as a direct result of colonization and dislocation from their Country in past generations. In Australia, cultural protocols exist relating to who can talk on behalf of or make decisions for Aboriginal people. Elders are highly respected as leaders and teachers and are active in the decision-making process. Becoming an Elder is earned through respect rather than an entitlement associated with age or family history. Consensus decision-making is often preferred and even a respected Elder from one nation does not speak on behalf of a community from another nation.

The opportunity for research came from a whole of locality integrated care pilot project to improve diabetes care for Aboriginal people (NSW Department of Health

2015). Partners included a regional public health service provider, the local Aboriginal Community Controlled Health Service, and the private primary care sector (then called Medicare Locals). A Steering Group with membership from all these organizations determined research to identify the model of care experienced by Aboriginal people in Dubbo should be undertaken so the model could be improved. The Steering Group also determined Intellectual Property and any accolades or benefits arising from the research would belong to all organizations and that all would need to endorse the research at key stages such as ethics and the publication of findings.

Each organization nominated one or more staff members to be part of the research team, and the research was to be conducted alongside usual clinical work. The research team consisted of two male Aboriginal Health workers (Bernie Kemp and Craig Johnson) who were qualified diabetes educators, two female Aboriginal Health Workers (Valerie Smith and Monica Johnson) and two non-Aboriginal women (Emma Webster and Billie Townsend). Between the team, there was over 60 years' experience in health and qualifications in nursing, diabetes education, research, and history. Individually, we were all novices in at least one aspect (research, diabetes, or cultural knowledge). Team members knew only one or two of the other team members, but all had strong community connections to Dubbo. Only one of the Aboriginal team members was Wiradjuri.

3 Design: "Who Else Should We Be Talking To?"

The first research team meeting focused on getting to know each other. Having strong existing community connections assisted in this process as we could identify common interests and connections quickly. Establishing trust was important as this allowed each individual to participate fully with no risk to their personal, professional, or cultural identities.

Tension 1: Risk to Identity The professional identity of the individual is an important element of the "scientific approach" versus a "culturally sensitive approach" where personal, cultural, and professional identities are all important and there is a strong sense of responsibility to other Aboriginal people.

Team members clarified during the initial meeting that they had agreed to participate in the research because they wanted to see an improvement in diabetes care for their patients. The meeting concluded with discussion about research and some brainstorming about data collection methods which would be engaging for Aboriginal participants.

Tension 2: Motivation for Research Producing knowledge is a valid reason to undertake research when coming from a "scientific approach," whereas this is not valued when a "culturally sensitive approach" is taken as it neglects the need for reciprocity. In this case, the research took knowledge, but put something back by improving diabetes care for Aboriginal people.

The philosophical underpinning of research was discussed as a group in that first meeting, not by using the accepted academic terms, but by discussing what was important to allow Aboriginal people to feel comfortable to participate in the research. The research was constructivist, accepting people create and recreate a social world (Crotty 1998), and it was decided to privilege Aboriginal cultural knowledge wherever this would make participants or researchers more comfortable.

Grounded theory (Birks and Mills 2015) was chosen as we were trying to depict the model of care experienced by Aboriginal people, and participatory methodologies (Bowen 2015) reflected well how we wanted to work as a research team. Choosing these approaches had the overall effect of equalizing the power between all researchers, who each took the lead when their various skills were best able to contribute to the research. This approach challenged existing research systems as ethics applications, manuscripts for publication, and conference presentations cannot be submitted without a lead investigator being identified. Yet, we had chosen to work collaboratively and not privilege any individual or assume that one investigator could speak on behalf of all. This was resolved to some extent by creating a collective identity for ourselves, the “Dubbo Aboriginal Research Team,” for conference presentations. However, research ethics and publishing systems still required a single contact and this role was fulfilled by the person with most research experience, as dealing with the research process and associated forms was not as alienating as they would have been for other members.

Tension 3: Lead Investigator A lead investigator is expected for research undertaken using a “scientific approach” including ethics applications and publications. A “culturally sensitive approach” required a collective identity which did not privilege any individual.

Cultural protocol is important, and it was respectful that elders and key agencies not only know about the research, but also had the opportunity to shape its design. Regular meetings with the research team addressed the question *who else should we be talking to?* which brought involvement of community into the design of the study. Members of the research team visited the Local Aboriginal Lands Council, Dubbo Aboriginal Community Working Party (both are formal entities with local cultural authority), and the Koori Yarning Group (an informal group where elders come together for social interaction) in the design stages. This helped shape the approach to participants, focus group structure, and incentives for participants. These groups kept the research focused on delivering benefits to Aboriginal people with diabetes.

Tension 4: Design of the Research The researcher with the most research experience would lead research design in a “scientific approach,” whereas our “culturally sensitive approach” actively asked community members to direct the design stage. We did this by asking *who else should we be talking to?* and incorporated their advice. In this way, cultural knowledge was valued alongside research knowledge.

4 Data Collection: “We Wanted It to Have a Social Feel”

An example of privileging cultural knowledge can be seen in our approach to inviting participants to be part of the study. Our research team attended community groups popular with Aboriginal people to introduce ourselves and explain the research. Members of the team went back to these groups on two to three occasions to build rapport and answer questions. Names and phone numbers of potential participants were collected and they were contacted when the next focus group was planned. This approach was chosen as potential participants would be more comfortable to decline being part of the research once trust had been established as it reduces the fear and any perceived power relationship.

Tension 5: Approach to Participants The usual “scientific approach” would suggest the least coercive approach to participants is that the approach is made by a person unknown to the participant. In our “culturally sensitive approach,” we determined the invitation to participate should come from a known person. This was seen as less coercive as the potential participant feels they can say “no” without penalty when they trust the researcher. The research team sought to establish this trust by meeting potential participants in environments where participants felt a sense of belonging and ownership.

Focus groups were piloted with a group of Aboriginal Health Workers. This enabled the research team to practice the roles of facilitator, organizer, and note taker and test that the questions would generate effective discussion. The pilot ran well, with excellent feedback and encouragement from the pilot “participants” which ensured the research team was comfortable that the approach would be successful and that there was clarity around the roles. This proved valuable as not every research team member could be present for all of the data collection events, and the team was easily able to change roles or help each other with the role. Focus groups were always facilitated by at least one Aboriginal member of the team.

Transport to and from focus groups was offered to all participants as many did not have their own transport and public transport was not readily available. Transport was provided by members of the research team. The focus groups were held in a local sporting facility on the riverbank, which, while central to town, is part of the natural environment. This was considered a “neutral” environment by Aboriginal people and had been the location of an Aboriginal reserve in years gone by (reserves were parcels of land set aside by the government where Aboriginal people were expected to live) (NSW Government Office of Environment and Heritage 2012). Some of the participants recalled growing up on the reserve.

The focus groups themselves had a strong emphasis on social relationships and reciprocity. Sessions started with a light snack and a cup of tea and conversation with all research team members in order for people to get to know each other. The research was explained to each person individually and informed consent given and demographic details collected. Focus groups were followed by a barbeque lunch

and a “Feltman” (Australian Indigenous Health Infonet 2015) education session conducted by one of the Aboriginal Health Workers who was a qualified diabetes educator. “Feltman” is a life-size person shaped felt wall hanging designed specifically for diabetes education. “Feltman’s” internal organs relevant to diabetes are clearly shown, and symbols for sugar can be moved around the body to give a pictorial description of the way hormones like insulin and glucagon work to store and release sugar in the body. The “Feltman” sessions focused on answering questions which had been raised in the focus groups, so each was customized to the needs of each focus group. Participants received a gift bag at conclusion of the session containing written information about diabetes management and the importance of having regular health checks. A voucher to a local fruit and vegetable shop to the value of \$10 was also included.

Tension 6: Reciprocity in Focus Groups The usual “scientific approach” would involve the researcher giving the participant a nominal incentive in return for data from or about the individual. In our “culturally sensitive approach,” reciprocity involved the exchange of information and knowledge. This was achieved by ensuring focus groups were followed by a diabetes education session tailored to the needs of each group. Social relationships were valued and enhanced with the opportunity to meet over morning tea and socialize at lunch time.

Five gender-specific focus groups were conducted (3 male, 2 female, total participants $n = 25$, $n = 12$ male, $n = 13$ female) as it was thought that gender-sensitive issues might be raised. It is believed that men’s business and women’s business should be kept separate in Aboriginal culture, and it can therefore be inappropriate to discuss some of these issues in the presence of people from the other gender.

Focus groups were run by the facilitator, who dealt out six “conversation cards” so a different participant had a turn to start with their story. Each conversation card had a different numbered question written upon it, and the participant would read out the question and answer it before other group members shared their thoughts. For example, the card two question was “Who were the people who helped you understand your diabetes?” The group facilitator had a master list of all the questions and could help read the question where required and prompt further exploration. A visual diabetes education tool called a conversation map (Reaney et al. 2012, 2013) was displayed to give visual prompts of the usual aspects of diabetes care. Visual representation of medications, types of diabetes, support groups, feelings, learning about blood sugar levels, complications, and exercise are just some of the visual prompts on the conversation map. Some of the participants were familiar with the conversation map as they had experienced this as part of previous diabetes education sessions. Both the conversation cards and the conversation map made the focus group very interactive with little direction required by the facilitator. Discussion in the focus groups was very rich, with audio recordings running from 85 to 108 min (see also ► Chap. 103, “Conducting Focus Groups in Terms of an Appreciation of Indigenous Ways of Knowing”).

5 Analysis: “All that Work for Just a Few Pages?”

All researchers coded the first transcript collectively. This was time intensive but meant that all members had a good understanding of the process and that the initial codes had a high level of interrogation before being labeled. Combinations of the research team coded the remaining transcripts. All transcripts were open coded by hand and then cut up and sorted. This made the coding process visual and tangible and allowed intellectual input from all members of the research team in a way that coding on a computer could not.

In grounded theory, constant comparison of codes and incidents is made as each focus group is conducted and new data are added (Birks and Mills 2015; Wong et al. 2017). The slow process of the group coding the first transcript meant that we had conducted our fifth focus group before finishing coding the first. We incorporated constant comparison of each subsequent focus group transcript, but this is not how grounded theory is meant to be done as it is not possible to test emergent theory in subsequent data collection events. The constant comparison process also drives theoretical sampling, where participants with certain characteristics are intentionally chosen to determine if the emergent theory holds (Birks and Mills 2015; Wong et al. 2017). In our case, we attempted theoretical sampling of two newly diagnosed people with diabetes, but this was unsuccessful. Grounded theory purists might argue that it is no longer grounded theory if these tenets cannot be followed. The decision to continue to collect data before having completed coding the first focus group was balanced against the importance of participatory methodologies and cultural values rather than the absolute primacy of grounded theory. It was decided that going with the community momentum and goodwill for the study, being inclusive of the research team in the coding process, and finally not approaching additional newly diagnosed patients were all justifiable. This last point was imperative as Dubbo’s only Aboriginal Health Worker’s qualified in diabetes education were members of the research team. Establishing a trusting therapeutic relationship with those newly diagnosed cases was determined to be more important than the research.

Tension 7: Divergence from Accepted Methodology The “scientific approach” to grounded theory privileges the method (constant comparison and theoretical sampling), whereas our “culturally sensitive approach” prioritized the enthusiasm for focus groups in the community and the need to include all research team members in the coding of the first transcript over the formal method.

Memo writing is a key analytic tool in grounded theory (Birks and Mills 2015; Wong et al. 2017). Three types of memos were used in this study. The first documented the group debrief after each data collection event, the second documented group discussion of coding and categories, and the third encapsulated a very brief overview (“top line” memo) of our thinking at occasional intervals. Visual diagrams of codes and categories were constructed during meetings, and these were photographed to document the evolution of the model of care experienced by Aboriginal people. The purpose of memo writing in grounded theory is to document the development of the thoughts of the researcher. Most of the analysis happened in discussion during meetings rather

than the writing in between meetings, and the writing and pictures simply documented meeting discussion.

6 Findings: “I Have a Good Relationship with My Patients, But they Have Never Talked to Me About that Before”

We had assumed at the commencement of our study that the model of care delivered by health services and health professionals would be the key factor in Aboriginal people coming to learn and manage their diabetes. Instead, we found that this was one of four factors, with the other three being the continuing effects of colonization on physical activity, nutrition and bush medicine, the power of learning about diabetes directly from family, and positive and negative interactions with the health service. This was an important finding for the research team as a whole, as it was new information not previously heard by members of the research team despite their experience, qualifications, and long and enduring relationships with many Aboriginal patients with diabetes. This was attributed to the difference between research-style questioning which is open-ended and positions the participant as the expert, rather than the clinical-style questioning which positions the health professional as the expert. In addition, the nonclinical environment, the social feel of the focus group, and the conversation map put participants at ease and facilitated the discussion on a broad range of topics.

A brief summary of findings yielded by this participatory and culturally sensitive approach is described below. A more detailed description and analysis can be found elsewhere (Webster et al. 2017).

Colonization was found to have a continued effect on health and lifestyle, with contemporary policies restricting desired hunting and fishing practices and dislocation from country resulting in lost access to bush tucker.

The government bloke was there trying to tell us that if we wanted to go out and shoot a roo and eat it, we had to apply to Canberra first, and one old fella (said)... ‘My kids want it tonight not next week or the week after’. (Travis FG1 920–929)

Seeing family members with diabetes shaped participant’s views on diabetes. Participants were well aware of diabetes and associated complications and learned about what diabetes was and how to manage it predominantly from family members through the cultural practice of intergenerational learning. The high prevalence of diabetes in Aboriginal families increased exposure to this experiential learning.

I saw my mother go through hell ... My mother died and my grandmother, her mother. She was totally blind by the time she was 60 and now it’s all reflecting on me. (Bianca FG4 88–92)

While some interactions with health services had been very positive, many participants described feeling stereotyped by non-Indigenous health professionals. Participants perceived they were not being heard and that the lack of cultural understanding by health professionals resulted in their reluctance to seek further help.

One of the worst things I come across is because I'm dark skinned, they think I drink and smoke, I never drank or smoked in my life. And the first thing they say is, they don't even ask the question of me 'You will have to give up the grog and smokes', and I said, 'Mate I've never tried it in my life'. (Ross FG1 1064–1067)

Where participants described receiving the general practitioner model of care, they found it highly acceptable. Pharmacists and Aboriginal Health Workers were the other health professionals who participants described as helping them learn about diabetes.

Really, really nice. . . I go every three months and I have a long appointment because first of all I go to the nurse then I go to (the GP) and the nurse weighs you and does all your sugars tells you everything and that and then from there I go to (GP). (Felicity FG4 223–226)

While many participants described difficulty finding support and sticking with programs, many made lifestyle adjustments after their diabetes diagnosis. All participants had goals relating to diabetes, and while there were various levels of control and understanding, many were extremely motivated to master aspects of the disease.

In the supermarkets I'm forever reading the packets, what do they call it? Carbohydrates 'cause carbohydrates is sugar as well and then underneath you can see sugar, and I always look at that to see how low it is before I buy it... I'm still doing things wrong, and I'm still learning. (Daniel FG3 217–222)

This study provided an explanation for health practitioners, services, and systems to understand how Aboriginal people learn about and manage diabetes (see Fig. 1). The model of care was a small part of learning to understand and manage diabetes for Aboriginal people. Other influences were historical factors such as colonization and witnessing family members suffering from diabetes and interaction with the health service.

Health system and service improvements which build on to the cultural acceptability of intergenerational learning such as supporting holistic patient centered and family centered models of care were recommended. Improving cultural knowledge of non-Aboriginal health professionals and ensuring Aboriginal voices can be heard in priority setting at a service level will improve service credibility with the Aboriginal community. Employing more Aboriginal people in professional roles and more Aboriginal Health Workers who are qualified diabetes educators helps Aboriginal patients feel they are understood.

7 Research Impact: "How Have Aboriginal People Benefitted from the Research?"

Group writing and presentation of research findings happened throughout the research. The focus on presenting the work from the beginning ensured group writing tasks commenced early in the research process. Group discussion and agreement shaped how presentations would proceed and what would be included. The preferred presentation style was collaborative, with up to five of the research

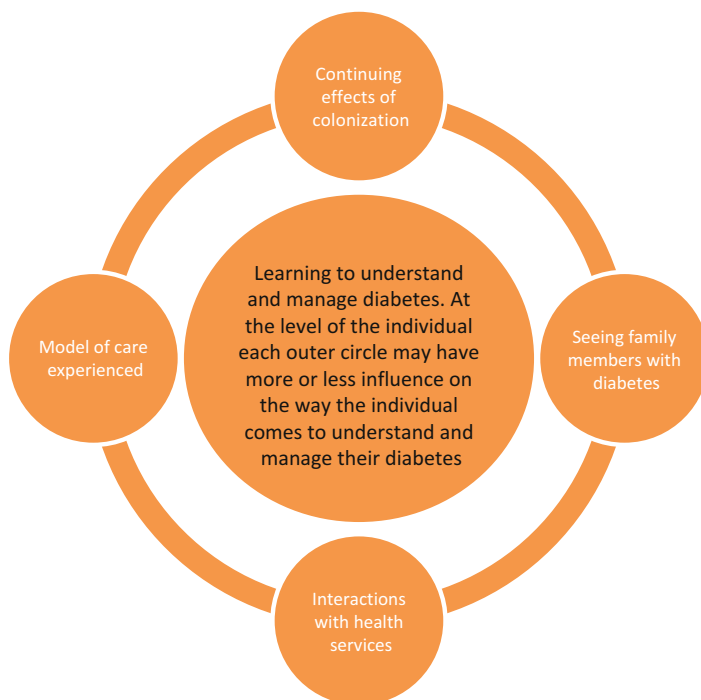


Fig. 1 Theory which explains an Aboriginal perspective of learning to understand and manage diabetes

team involved in a single presentation. All presentations were scripted to ensure multiple presenters did not detract from overall coherency for the audience. All members of the research team were involved with checking and practicing scripts and presentations. This actively involved research team members and contributed to the joint development of ideas and understanding as the research progressed. The presentations were visual and included many photographs and diagrams. Participant quotes read by Aboriginal colleagues were embedded as audio files to bring the cultural tradition of oral knowledge to the presentations.

Regular formal communication with the Dubbo Aboriginal Community Working Party continued throughout the research in addition to informal verbal updates with key individuals. The Working Party kept the research team focused on the importance of improvements in diabetes care for Aboriginal people. The research team presented findings to local hospital and primary health care medical, allied health, and nursing professionals. Presentations were also made to state and national clinical and academic audiences (see Fig. 2 Dissemination summary for detail). A formal report was prepared for partner organizations and a manuscript was prepared for peer review.

For many research projects, achieving the dissemination summary described (see Fig. 2) would be sufficient and signal the final phase of the research. For our study,

Oral presentation of research in progress or research findings or both

- Local Aboriginal Community Working Party
- Local Aboriginal Diabetes Support Group and Carers Support Group
- Local health services (hospital and primary care settings for medical, allied health and nursing staff)
- Diabetes integrated care working party (membership included senior managers, clinicians and patient representatives)
- Local Health District Aboriginal Health Worker Forum
- National Rural Health Conference
- NSW Rural Health and Research Congress

Written publication of research findings

- A full report was circulated to the organizations who formed part of the original working party and the Research Ethics committees who endorsed the research
- Publication in a peer reviewed journal

Fig. 2 Dissemination summary

this did not fulfil the mandate to improve diabetes care for Aboriginal people desired by research team members, the Dubbo Aboriginal Community Working Party, and others.

There have been a number of improvements thus far. An Aboriginal Chronic Disease Support Group has been established, led by Aboriginal Health Workers. Meetings are held monthly in a community setting and a number of agencies work collaboratively to make meetings a success by referring patients, transporting participants, arranging morning tea and lunch and monitoring blood pressure, blood sugar, and weight. Health professionals from different health services attend as guest speakers and stay for the duration of the session to build relationships with participants. A local general practitioner attends regularly, bringing a medical student on clinical placement when available. Support group members report they feel listened to and appreciate the concern shown by the health professionals. They also regard it as a privilege to be involved in the education of future medical personnel. The running of the Support Group represents much stronger collaboration at a service level than had happened previously and has provided a forum for Aboriginal people to learn in a family centered way from each other as well as from health professionals.

Members of the research team have been invited to join a Dubbo-wide leadership group to improve diabetes care. The focus of the leadership group is on improving communication and referral between services, locality-wide workforce education, and service reform. Some small local service changes have taken place, such as Aboriginal Health Worker's being able to contact general practitioners at a single medical practice directly when concerned about the need for medication changes for patients.

Other benefits from the research included the development of research skills for members of the research team and an increased interest in research generally. There

has been an increase in the respect for Aboriginal Health Workers by both the community and the services they work for. The Dubbo Aboriginal Community Working Party has suggested their members work with medical staff and students at the local university to develop “yarning style” medical consultations and has invited one of the Aboriginal Health Workers from the research team to continue to provide regular updates on progress. Yarning is a relaxed, sharing conversation between two or more people. Yarning might include finding out more about the person and finding common interests, understanding each other’s community or kinship connections and sharing stories.

Tension 8: Value of Published Findings The usual “scientific approach” to research would value publication of research findings in the academic literature as the most important research output. In this way, the “scientific approach” values intellectual property highly. Our “culturally sensitive approach” showed that presentation of research findings back to the community and decision makers and the subsequent changes in practice was most important. The culturally sensitive approach, therefore, valued meaningful improvement in service delivery over publication of findings.

We cannot provide unequivocal evidence to show locality-wide improvements in diabetes care for Aboriginal people as a result of this research. However, the research has raised the profile of diabetes care for Aboriginal people, members of the research team continue to be actively involved in service improvements and the research continues to influence decisions made at an individual and a service level. This extension of involvement beyond publication is part of the expectation of reciprocity and giving something back.

Research impact measurement for studies undertaken with Aboriginal communities continues to develop, with questions about whose right it is to determine research impact and meaningful measures of capacity building, engagement, and reciprocity at the center of the debate (Tsey et al. 2016). This has been discussed by the research team who determined that while good progress has been made, we have not achieved enough improvement in diabetes care to discharge our sense of responsibility to participants or each other.

8 Applying an Active Decolonizing Gaze: Conclusion and Future Directions

This chapter set out to describe how we brought a “decolonizing gaze” to the usual “scientific” research practices. Prior (2007) proposes colonization by research occurs when research restricts cultural representation by dominating and suppressing the other. Colonization by research could, therefore, occur at any or every stage of the research process. Decisions of what can be considered authentic knowledge (epistemology), suitable approaches to inform how the research should proceed (methodology) and ways of collecting data (methods) all have the potential to

dominate and suppress. Likewise, explicit or implicit judgments are made about values (axiology) and morals (ethics).

By contrast, decolonized research would be directed and undertaken by Aboriginal people consistent with their world view, specifically to benefit the participants and guided by the values of spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility (Prior 2007; Aboriginal Health & Medical Research Ethics Committee 2013; Sherwood 2013; Gray and Opreescu 2015). Judged by these criteria, we have fallen short. Honoring the decolonizing gaze was difficult, as many structures such as organizational decision-making (where policy and managers determine priorities), applying for ethics and publication of research findings (requiring a lead researcher) undermined our efforts to work collaboratively and to minimize the power relationships both among the research team and with the community.

Yet, taking a “decolonizing gaze” facilitated participation of Aboriginal people in our research. We were successful in embedding reciprocity in both methodology and method. There was a focus on the value of collective knowledge, the importance of relationships and culturally sensitive data collection methods. Aboriginal researchers developed research skills and non-Aboriginal researchers enhanced their cultural knowledge. It will be possible to build on these successes by continuing long-term research partnerships between health services, academia, and the community. Theoretical models such as engaged scholarship which is driven by principles of reciprocity, mutual benefit, and multidirectional learning to solve social, civic, and ethical problems may prove useful (Bowen 2015). Participatory research has an explicit commitment to collaborative value generation, co-creation of design, and co-production of knowledge (Higginbottom and Liamputtong 2015; Jackson and Greenhalgh 2015). It is assumed strong research transfer occurs when using this approach.

Like others (Kendall et al. 2011), we have found a need to be flexible through the conduct of the research. It was not possible to anticipate all rules for the conduct of the research in advance. Tensions between a “scientific approach” and a “culturally sensitive approach” were faced at each stage of the research process and were resolved by discussion among the research team privileging the cultural comfort of participants, Aboriginal members of the research team, and the Aboriginal community. This approach facilitated involvement of Aboriginal people in research.

Imposing research designs and practices on Aboriginal people and communities without consideration that each community is unique has the potential to cause further harm and disempowerment. Applying the “decolonizing gaze” meant valuing an Aboriginal way of knowing which influenced all aspects of our study design and procedures. Participatory research methods allowed high quality, outcome-driven research to be undertaken with a team of people who have varying levels of cultural understanding and experience with research. Using participatory methods facilitated Aboriginal community involvement in the design and ultimately to benefit from the research.

We would echo Sherwood’s call to researchers. There is enough knowledge out there and it is time to apply our scholarship, community links, and good will to bring about change to research processes to drive improvements in health outcomes for Aboriginal people.

We provide below some tips which facilitated participation of Aboriginal people in our research. We have also included reflection on what could have been done better so the reader can consider and incorporate into future research.

8.1 Tips to Facilitate Participation of Aboriginal People in Your Research

- Become familiar with cultural protocols for your community. Ask the question of each other and those you consult with “Who else should we be talking to?”
- Think of experience, knowledge, and qualifications as a collective as this strengthens confidence and trust that you will know how the research should proceed when the time comes
- Commit collectively to a philosophy in the beginning and trust that this will support you all to make the best decision when needed
- Commit collectively to how you want meetings to proceed. In our study, we tried to make meetings suit everyone, but ultimately if someone could not attend, the meeting still went ahead with the absent member catching up with the details at a later stage
- Use visual prompts in data collection, such as the conversation map and conversation cards, to enhance interaction in focus groups
- Present on the research as a group throughout the research process as often as you can as this involves everyone in the analytical process and facilitates the evolution of your thinking
- Involve everyone in the coding and allow more time as it will take longer, but it also maximizes intellectual input from all members
- Use visual methods such as diagrams, white boards, and photographs to document collective progress with analysis
- Develop community connections before you start thinking about research

8.2 Things We Could Have Done Better

- Our approach to reflexivity involved group discussion of what worked well and what could be improved. This could have been enhanced by reflexive practice at an individual level if we had explored what was uncomfortable or comfortable and reflecting on own beliefs, knowledge, and assumptions
- In hindsight, our focus groups did not need to be gender specific as both men and women showed concern for each other and were interested in hearing experiences and opinions of the other gender
- While using Grounded Theory facilitated a broader understanding of diabetes and was an entirely sensible approach, it was a difficult methodology for novice researchers because of the complexity of the terminology and to some extent the rigidity of the form. Ease of methodology for the research novice should be considered when designing the study.

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Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women

91

Chijioke Obasi

Contents

1	Introduction	1580
2	The Research Project	1581
2.1	Research Design	1581
2.2	“Africanist Sista-Hood in Britain”: An Evolving Theoretical Framework	1581
2.3	Learning from the Pilot Study	1584
3	Data Collection	1585
3.1	Access	1585
3.2	Interviews	1586
4	Inside Looking Out or Outside Looking In?	1587
4.1	Situating the Researcher in the Research	1587
4.2	Situating Participants on the Insider/Outsider Continuum	1589
5	Connecting to Africanist Sista-Hood in Britain	1592
5.1	Names, Self-Naming, and Naming Identity	1592
5.2	Space and Place in Africanist Sista-Hood	1595
6	Conclusions and Future Directions	1597
	References	1598

Abstract

The chapter discusses issues of identity in research. It does this by examining the impacts of the identity of the researcher, participants, and the various identity interchanges that take place. This chapter draws on the perspectives and experiences of participants and researcher in a PhD study with five (Six Deaf women were interviewed but one withdrew due to a conflict of interest.) culturally Deaf (white) women and 25 Black (hearing) women discussing their world of work in UK public sector organizations. The theoretical framework of “Africanist Sista-hood in Britain” is that which underpins the positioning of the research and

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researcher. The chapter provides a reflexive account of the research but in a way that centralizes participant perspectives. Two goals have been achieved; firstly, it adds further contribution to the insider/outsider debate by adding participant perspectives on the issue, and secondly, it demonstrates the ways in which the theoretical framework of “Africanist Sista-hood in Britain” can be used in research not just with Black women but also via collaborative approaches with other social groups. In so doing, the chapter raises a number of important questions: Should researchers seek out participant perspectives on the insider/outsider debates in research? In what ways does the identity interchange between researcher and researched have an impact on the research process? What does Africanist Sista-hood in Britain have to offer to Black women and others carrying out research in the field?

Keywords

Insider/outsider research · Black women · Deaf women · Africanist Sista-hood · Black feminism · Womanism · Africana womanism · Deaf research

1 Introduction

In this chapter, I discuss the way a researcher’s identity as a Black female, hearing researcher has an impact on the research processes with Black women and culturally Deaf women within the same PhD study. Central to the chapter are discussions of participant perspectives on insider/outsider researcher positioning and “sameness” and “difference” in research. The chapter adds significant contribution to existing discourses by centralizing participant perspectives, as well as adding discussions on Deaf/hearing insider/outsider positionings which have largely been absent from the field. It introduces the framework of “Africanist Sista-hood in Britain” which underpins the study. It uses participant contributions to make links to the central tenets as a source of validation of the developing framework. Alliances are also formed in Deaf cultural discourse in an attempt to foreground cultural and linguistic understandings of Deaf people. In working with these two participant groups, neither Deaf cultural discourse nor Africanist Sista-hood would be adequate in isolation. However, in creating theoretical alliances between the two, there is relevance in the frameworks for analysis for both participant groups.

The Deaf women in the research are culturally Deaf women. Within deaf studies literature, there is much debate about Deaf identity and the ways in which culturally Deaf people form a cultural and linguistic minority group that differs from dominant hearing perceptions of deaf people as disabled. In incorporating cultural Deaf discourse, I write about the distinct Deaf communities who refer to themselves less as disabled as is the dominant hearing articulation, rather their own lived reality is that of members of a cultural and linguistic minority who share a pride in their signed language and cultural norms that are distinct and in some cases in opposition to that of the majority hearing society (Ladd 2003; Lane 2005; Bahan 2008; Padden and Humphries 2005; Bauman and Murray 2014a). Deaf pride in their culture and the efforts made to maintain and nurture it are absent from the dominant

constructions of Deaf people as disabled. When writing about culturally Deaf signing individuals or communities, the convention introduced by Woodward (1972) is to write the word Deaf with a capital D and so maintaining a distinction from deaf people outside of this culture who would not describe themselves in this way. This is the convention I will follow in this chapter.

The chapter starts by introducing the research project with discussions on research design, access, pilot study, data collection, and changes to the design post-pilot. Integral to this are discussions of the theoretical framework, its foundations, influences, and scope for research. The chapter draws heavily on participant data to discuss the views that Black women and Deaf women shared on “insider/outsider” positions in research. It does this in a way that incorporates discussions of researcher/researched identity, positive aspects of assumed *common bonds* that can occur between Black female participants and Black female researcher (Johnson-Bailey 1999), and the parameters that should guide hearing with Deaf research.

In the final section of this chapter, participant data is used to validate the theoretical framework of Africanist Sista-hood by demonstrating the ways in which individual identity of Deaf women and Black women is still connected to historical identities of their collectives. It draws on examples from the data about names and self-naming, place and space, and the way this is regulated both physically and professionally both for culturally Deaf women and Black women within their work spaces.

2 The Research Project

2.1 Research Design

The research forms part of a PhD study focussing on perspectives and experiences of equality and diversity in the UK public sector. It seeks to examine whether the rhetoric provided by public sector organizations are validated via the experiences and perspectives of Black women and Deaf women who work within them. It falls within an interpretivist paradigm using a framework of Africanist Sista-hood in Britain, Deaf cultural discourse, and using qualitative research methods.

The primary focus of the study is Black women working in the public sector across a range of organizations. Learning from the work of Patricia Hill Collins, within the framework, is the recognition of the need to acknowledge both individual and collective views on our experiences as Black women while also working in alliance with other marginalized groups for wider social justice (Collins 2000). In this case, the allied social group is culturally Deaf women.

2.2 “Africanist Sista-Hood in Britain”: An Evolving Theoretical Framework

I have written in detail about Africanist Sista-hood in Britain (Obasi 2016a) but for ease of reference, I have summarized some of that work within this section.

Africanist Sista-hood in Britain was developed as a result of both top-down and bottom-up approaches to theory. Gibson and Brown (2009) describe top-down theory as any theory that has been formulated prior to the empirical work and bottom-up theory as that which is created through the exploration of data. Working within new terminological frames the framework builds on the work of Black feminists, womanists, and Africana womanists to merge this with organic developments in the process of data collection and analysis in the research.

For many Black women, the search for an analytical framework that centralizes our individual and collective experiences and perspectives has ended with the developments of theories in Black feminism. However, influences of American history and legislation means that direct application to the UK context can be more problematic (Mirza 1997; Young 2000; Reynolds 2002; Dean 2009). Black British feminism does seek to address this issue, but it is the particularities of the British context that brings with it issues of contestation of who is considered Black which are also translated into Black British Feminism. Yet, there are still a significant number of Black women who have declared their dissatisfaction with the theory and more resolutely the terminology of feminism no matter its variant. The history of feminism with the privileged status of white middle class women and the marginalization of Black women makes feminism a bitter pill for many to swallow. Womanism (Walker 1983) has for some provided a useful alternative but in Britain has had much less appeal or recognition (Charles 1997).

“Africanist Sista-hood in Britain” offers original terminology while highlighting points of connection with and divergence from existing theories in an aim to regenerate long-standing debates about epistemological and ontological understandings of Black womanhood. It recognizes the specific location of Black women in Britain and is reflective of the “race,” class, and gender relations as well as other intersections that affect us. It does this by drawing on existing frameworks in the field and calling for further contributions to an organic framework.

Crotty (1998), in his much cited work explaining the foundations of social research, describes the way in which researchers can draw on established methodological works to develop one specific to the research in hand. Guest et al. (2012) provide an analogy with the work of Bruce Lee in developing his own fighting style due to his dissatisfaction with existing styles. In so doing, he has not developed a new fighting style but synthesized the most useful techniques from numerous existing ones. In reflecting on this fighting style, Lee describes it as something that is fluid and flexible inviting practitioners to take from it what they choose rather than trying to follow a prescribed process. In Africanist Sista-hood in Britain, a similar fluidity is built in. It is a fluidity that allows for incorporation of the work of our Sistas without being constrained by the frames of feminism.

In moving away from feminist terminology, it is not in an attempt to deny the numerous achievements of Black feminists and womanists to whom we should all remain eternally grateful. Rather, it is an attempt to continue and build on that work but in a way that responds creatively to those both within and outside feminist discourses who have declared their dissatisfaction with the legacy the history and terminology still leaves. Black feminists themselves have recognized the limitations

of the terminology of feminism (Hooks 1984; Collins 1996, 2000; Springer 2002). As Davis (2004, p. 95) points out, “we need to find ways to connect with and at the same time be critical of the work of our foremothers.” Many Black women have voiced their rejection of feminist terminology, yet this issue has not been adequately addressed by Black feminism. Jain and Turner (2012, p. 76) state: “When we look at the term feminist through the lens of the politics of naming we see that it is not an impartial label and that there are multiple reasons why women are reluctant to identify with it.” The dissent that has been voiced for many decades both in Western and so-called Third World Black women’s discourses still remains active and unsatisfied.

“Africanist Sista-hood in Britain” is a term that is quite deliberately proposed for a number of reasons and can be broken down into its component parts. The term “Africanist” relates directly to Diaspora, and in doing so, connects us back to the direct or (an)Sista-ral heritage in Africa. An Africanist perspective sets out clear and unambiguous messages about embracing African (an)Sista-ry. In this sense, it differs significantly from the contestations that exist around political use of the term Black in the British context which is incorporated into Black British Feminism.

“Sista” is a term recognized within Black popular culture in the UK and beyond, but is also a term that has historically been articulated within Africa and as part of the migration journey for many Black women in the UK. To be a Sista is different from being a sister as within the term Sista is an implied recognition of a positive association with Black womanhood.

Like womanism and Black feminism, for Africanist Sista-hood, any perspective aimed at ending sexist oppression of all women must also embrace issues of intersectionality in relation, not just to “race” and class, but to issues of oppression facing all social groups (Collins 2000). For many Black women, “race” and gender are aspects of our identity that are recognized as constantly visible, but the intersectional and fluid position of our identities also contributes to the diversity that is Black womanhood. The fight for social justice must remain a central focus in any emancipatory framework. Africanist Sista-hood leaves space for recognition of the shifting nature of oppression which dictates that other forms of oppression may impact on groups and individuals within those groups to a larger extent than sexism and may impact simultaneously as part of their everyday lives.

The “-hood” component of the term is about the collectivity and connectivity which is a driving force behind the concept. It has at the center the values of internal validation, self-definition authentication, creativity, and elevation of subjugated knowledge. Lived experience is a central tenet in which validation and authenticity from within the Sista-hood is gained. Within Africanist Sista-hood it is important to build in the safeguards against this loss of control from those guilty of “knowing without knowing” (Collins 2000, cited in Reynolds 2002). It is recognized that every individual, male or female, Black or white, has a contribution to make, but without the recognition of the importance of both *knowledge* and *experience*, the validity of those contributions will be limited and may need further validation.

Unlike Black British feminism, it is a discourse “in Britain” rather than one centered around a British identity as exists in Black British feminism. It also focuses

on the location in Britain rather than restricting it to women with British citizenship. It is inclusive of Africanist women living their life in Britain, but who are either not legally British citizens or do not wish to readily showcase that aspect of their identity given the tumultuous history of British “race” relations (see greater details of this theoretical framework in Obasi 2016a, b).

2.3 Learning from the Pilot Study

Details of the pilot have previously been published (Obasi 2014). Within that publication, I discussed some of the possible benefits of a pilot study, and indeed in this research, the pilot proved very valuable in testing out the theoretical framework, research methods, and analysis. It was also useful to highlight some preliminary findings and use some of these findings and participant perspectives to contribute to further redesign the study as well as improve data collection methods.

In relation to the Deaf interviews post-pilot, in addition to my own reflections, I sought out discussions with other (Deaf and hearing) academics that suggested analysis straight from the data would be a more beneficial approach that might also tackle some of the issues in relation to being *lost in translation* (Stone and West 2012; Obasi 2014) as well as the issues of language and power in research discussed by Temple and Young (2004) and Young and Temple (2014). There are some arguments put forward by Gibbs (2007) that researchers can actually benefit from working directly with the data in any research project rather than working through transcriptions. In this case, some of those advantages were in relation to my need to continually return to the data to check for the signed quotes, which led to continual review of facial expression, intonation, and intensity which all form part of the meaning in British Sign Language (BSL). This all increased authenticity and familiarity with the data.

The decision on how to represent signed data was also a very difficult one, and one in which I have changed my position a number of times. There are a number of equally valid but sometimes opposing perspectives and practices in the area. Signed languages have been willfully suppressed in favor of spoken or written languages (Ladd 2003; Bauman 2008; Ladd 2008; Obasi 2008). In the case of academia, where most of the Deaf women worked, this position is exasperated even further (Bauman 2008; Stone and West 2012; Young and Temple 2014). The decision in moving from signed to a written representation of the language in and of itself can be seen as further contributing to this. Temple and Young (2004) discuss issues of the dynamics of power in relation to minority and majority languages, and the processes that take place during the translation of interviews. They point to the way that transcription into the dominant English language can also have an invisibilizing effect on the source language when translating research interviews. Young and Temple (2014, p. 145) go further and state that “the language that is less powerful is made to disappear and by implication so too do the users. . . . the seemingly straightforward and expedient research practice of transcription is akin to epistemological and ontological vandalism.”

Ladd (2003), in his ground-breaking work on Deafhood, also takes a ground-breaking approach to representation, as in some cases not just BSL grammar but also nonmanual representations are written into the quotes of his participants, in way that represents true authenticity. Given the framework, authenticity would be my natural aim. However, there are other issues to consider including issues of authority and voice, raised by Hole (2007a) in a similar endeavor as a hearing woman interviewing Deaf women in sign language. As a nonnative signer I am not confident I could achieve the equivalence of Ladd (2003).

Another consideration raised by Young and Temple (2014) is about the negative impacts that can result from researchers' attempts to follow source language grammatical structure in a written representation as this could reinforce stereotypes of illiteracy, and in the particular case of Deaf people can be inappropriately linked to the "dumb" label inferring stupidity. Najarian (2006) also points to the potential to "trip up the reader" where a signed grammar is followed. For the most part I have opted for a full English translation of the quotes but on occasion left in "a BSL flavor" where the opportunity lends itself.

3 Data Collection

3.1 Access

In terms of access, a form of snowballing was used where participants were asked to recommend others for the research (Liamputtong 2013; Patton 2015). This was a preferred option because of the view that by implication the participant also recommends the researcher as well as endorsing the research. This is particularly important within the Africanist Sista-hood framework as it strengthens the idea of validation from within the collective of the social groups identified.

Linking again to the theoretical framework, as discussed by Browne (2005) in her research with nonheterosexual women, snowball sampling is a method that enables participants to have an ongoing influence on the research beyond their contributions in the interviews. Biernacki and Waldorf (1981) go as far as to say that participants become de facto research assistants. Young and Hunt (2011) write about the way that culturally Deaf perspectives have been excluded from research agendas where Deaf people are seen as objects of data collection rather than shaping the research and what is asked. Snowball sampling, therefore, in some ways provides an opportunity to allow this contribution. This method was particularly attractive to this research because of the opportunities it provides for both validation and monitoring based on the assumption that participants would only recommend others if they had had a positive research experience and felt the research worthwhile (Browne 2005).

In snowball sampling, potential issues of bias and other limitations discussed in the literature (Biernacki and Waldorf 1981; Merton 1972; Browne 2005; Sturgis 2008) have not been overlooked. Snowball sampling does have limitations which it is important to recognize, including the potential for bias that might result from those that are put forward as well as exclusions and boundaries created for those that are

not (Biernacki and Waldorf 1981; Browne 2005; Sturgis 2008). The potential exists for participants to put forward only those they feel will support their own position and this cannot be ruled out. However, there were instances of participants making suggestions of other participants who, once interviewed, seemed to represent completely different and sometimes opposing standpoints.

In addressing issues of validity, Faugier and Sargeant (1997) recognize potential bias as “a price which must be paid” in order to gain an understanding of participants and their particular circumstances. In addition to this, there were also limitations in terms of generalizability of findings (see also ► Chap. 5, “Recruitment of Research Participants”).

3.2 Interviews

Willis (2007) describes research methods as an expression of the research paradigm. I took a qualitative approach to the research, with in-depth interviews for data collection, moving from loosely structured interviews in the pilot study and early fieldwork, to more semi-structured interviews towards the end of the study (see Serry and Liamputtong 2017; see also ► Chap. 23, “Qualitative Interviewing”). Given the framework of Africanist Sista-hood in Britain and its recognition of both collective and individual experiences of the participants, focus groups were also planned to provide the opportunity for collective as well as individual responses (Liamputtong 2011). The plan was that the focus groups were to be made up of a sample of those who had already taken part in the interviews.

At the start of the research, my aim was to interview 20 women in total, at least 13 of whom would be Black and at least seven of whom would be Deaf (also recognizing the possibility that some may be both Black and Deaf). The final number of Black participants in the one-to-one interviews was 22. Two focus groups took place with Black women; in one of these focus groups there were an additional three women who did not take part in the one-to-one interviews, bringing the total Black participants to 25.

The snowball started with Black women already known to the researcher and was very successful, with participants generally providing me with the contact details of the next prospective participant after first having sought their permission.

The snowball sampling was not so successful with Deaf participants and the target number of seven was not met. Six Deaf women took part in the one-to-one interviews. Participants provided names but did not generally contact on my behalf first. There was, however, one exception where one Deaf participant went as far as to send out a flyer to her contact lists on my behalf which included my contact details and indeed one participant did contact me for an interview via this method. In addition, one of the participants suggested that I make a signed video of the flyer to be sent out to Deaf participants. However, although one person did respond to this video the interview did not take place in the end because of problems of a lack of availability. In addition, I was not successful in my attempts to hold a focus group

with Deaf Women. Participants worked in both professional and nonprofessional grades across the public sector.

In total, 30 participant interviews were used as one of the Deaf participants withdrew due to a conflict of interest that later developed. It is unfortunate that this was the only Deaf participant that was not white as this had added to the diversity and richness of data that was collected. In addition to the participants, I was also supported by a Black Deaf female friend who helped develop some of the signs around the concepts being discussed. As some of the terminology was new, there was no easy equivalent in British Sign Language. Having a Black Deaf perspective on this proved invaluable in terms of dissemination presentations I have done.

As I am a qualified interpreter, I made the decision to conduct the interviews with Deaf women in sign language, bringing me closer to the participants and these were video recorded. Interviews with Black women were in spoken English and voice recorded.

Some preliminary findings from the pilot study were discussed. Participants generally viewed equality and diversity policies within their organization with some level of skepticism with many using words like “tick box” and “tokenistic” to describe their view. There was evidence that participants held cultural and linguistic understandings of Deaf identity rather than disability. The concept of “workplace racial trauma” as well as “chronic racial insults” (Obasi 2013) were discovered where the trauma of racial discrimination leads to an exit from the workplace, and the chronic racial insults being lower level acts of bias, exclusion, and/or stereotyping that participants experienced on a more frequent basis. Chronic racial insults are most similar to the concept of micro invalidations as described by Sue et al. (2007) in their wider discussions of racial microaggressions. The Deaf participant discussions about the additional barriers they face in relation to, for example, the effects of working in English as a second language (British Sign Language being their first language), organization of interpreters, particular barriers in academia and publishing, etc., were interpreted as “the Deaf premium.” The discussion about the advantages given to hearing, signing colleagues was interpreted as “occupational circumvention.” Issues of “race” were made difficult for Black participants to discuss and as such were similar to the race taboo identified by Gordon (2007).

4 Inside Looking Out or Outside Looking In?

4.1 Situating the Researcher in the Research

Like Maylor (2009), being Black and being female is central to who I am as a researcher. It is also central to who I am as an individual. These aspects of my identity will always be visible and have an impact on how I am perceived by the research participants. However, given my research area, my position as a hearing person, which is often taken for granted outside of my working life, also becomes

much more significant in conducting the research with Deaf women. During the research with the two different groups of women, with regards to my own identity and the access that it gave me in terms of the importance of *experience* (Collins 1998, 2000), there were clear shifts in positioning that challenged my own location casting me both as “insider” and “outsider” in the same research study (see also ► Chap. 92, “Researcher Positionality in Cross-Cultural and Sensitive Research”). I found, as Johnson-Bailey (1999) states, that the interviewer/interviewee relationships had deeper foundations and were more intimate when there were fewer margins to mitigate (Obasi 2014).

Fawcett and Hearn (2004, p. 203) have described debates about otherness in research as something that is “ongoing, unfinished and probably unfinishable.” There has, in recent years, been a growing discourse from academics about insider and outsider debates in research (Mullings 1999; Brayboy 2000; Brayboy and Deyhle 2000; Merriam et al. 2001; Serrant-Green 2002; Innes 2009; Maylor 2009; Ochieng 2010; Gair 2012; Obasi 2014; Suwankhong and Liamputtong 2015). Within these writings, researchers generally provide reflexive accounts of their own position or a summary of the literature, whether or not this is based on the remarks or interactions with participants. However, this chapter takes an original approach in that it centralizes participant perspectives on this issue in a way that adds valuable contributions to this ongoing debate.

It has been argued for some time that it is impossible to separate the researcher from the research or knowledge from the knower (Andersen 1993), and at least in qualitative PhD research, engagement with reflexivity is increasingly becoming a requirement of completion (Obasi 2014).

According to Gair (2012, p. 137) “the notion of insider/outsider status is understood to mean the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group.” Within her paper, Gair talked about “common wounds” experienced both by researcher and participants, which was seen as a positive element to bring to the research relationship. It is clear from some of the responses from the participants that this was a position being afforded to me because of my status as a Black woman. What follows is a reflexive discussion centered on participant responses to insider/outsider perspectives on research.

There have been some examples in the literature where other Black women have discussed the way in which their identity as the researcher has formed part of the participant discussion (Johnson-Bailey 1999; Mullings 1999; Serrant-Green 2002; Maylor 2009; Ochieng 2010). In my own case within this study, similar instances occurred. An example of this is demonstrated by the participant below in her discussions about who should or should not be included within the label BAME (Black Asian and Minority Ethnic):

It is so broad right it is Black, Asian, minority ethnic so it is very very wide and there are people who use it to play a game to their advantage. For example there is someone, there is a programme that is run to help BAME people and this guy applied to go and he says he is ethnic minority. He is Jewish; he already has an advantageous position being a white

man. well I shouldn't really say it but there is nowhere for the likes of you and me to hide. If you see what I mean,...We are what it says on the tin! (Devandra, (For reasons of confidentiality and anonymity all participants have been given pseudonyms.) Civil servant).

There were many more similar examples where my identity formed part of the discussions, some of which are provided in other parts of the chapter.

4.2 Situating Participants on the Insider/Outsider Continuum

In addition to incidental references to my identity, and as I continued to think reflexively about my researcher position throughout the research, I felt it important to gain some understanding from participants as to their own perspectives on insider/outsider research. I introduced questions and discussions around sameness and difference of the researcher. Some generic responses were given and two examples are provided below:

Really it depends on the person. In an ideal world yes signing Deaf person, also their identity their experience growing up. Some might say "oh definitely Deaf" but some Deaf are '**deaf by ear**' . . . but are they the best representative for us Deaf signing community? Some hearing that know nothing about Deaf- definitely not!....also they must acknowledge give back something.so hearing not allowed? I won't say that, it depends on the person and the benefit to the signing community. . . . Also it's difficult because Deaf education is poor. Deaf with knowledge and qualification to become researcher are few so we have not much choice. We can't wait fifty years for the education to be sorted out and Deaf become researchers because that would be too late. (Mary, Academic).

Or a Black participant response:

I would have asked myself the question can this person really get a sense of what it's like for me as a Black female only because it's a different experience although they may empathize it's a totally different experience isn't it? I would have been curious as to why a white person felt the need to explore this. I would have asked the question why is it so important for you to be doing this? So I don't think I would have ruled it out because I would have been curious. Because white people have done research about Black people but it's not always been successful. (Debra, Counsellor).

From these two quotes, it would appear that there is some recognition of trust that can be won or lost by the researcher. For "insiders," the starting position is of trust that can be lost, for example, through the recognition of being "deaf by ear," and therefore, showing a lack of understanding of culturally Deaf perspectives. For "outsiders," there is recognition that trust can be won via willingness to be held to account and explain motivations for the research, or a willingness to give something back to the community the researcher is taking from. There is also recognition of the history of power and exploitation that needs at least to be acknowledged.

While it is important to be able to ask difficult and challenging questions about power dynamics in researcher/researched relationships during the research process,

I would say it is impossible to ask such questions without shining a spotlight on the identity of the researcher themselves. Within my own research, there were many more examples of responses where my own identity was central to the response made. This was regardless of whether I was interviewing Deaf women or Black women as seen in the examples below.

Chijioke: What do you think of hearing people doing research with Deaf people?

Louise: Honestly?

Chijioke: Yes please do.

Louise: Honestly, would be better Deaf. But you alright you know background Deaf you interpret yourself that's fine I have no problem with that. Hearing person just interested in learning? I would object to that. ...better that person can know and empathize (Louise, Administrator).

Similarly but relating to my identity as a Black woman:

Yes it does help because I know that you've had, well I shouldn't really assume really I shouldn't assume. It is likely that you would have gone through racist or you would have experienced some level of discrimination whereas you know one thing which I have been told over the years since I have been working for this local authority is that "no we don't understand what you're talking about because we're white" and I'm like "you're not even trying"I have worked with people who are white who put in effort to understand or can identify because of whatever experiences they may go through or in the family or a friend they can draw on that (Tochi, Social worker).

In an earlier paper (Obasi 2014), I discussed a Deaf participant response that was more challenging in questioning the legitimacy and negative impacts of hearing on Deaf research, but in both of these examples above, in addition to highlighting aspects of my own identity, there is also some distinction being made about those in the majority populations being discussed. They are differentiating between those who are part of the majority group (hearing people and white people) but who have some access to "knowledge" of the minority group be that professionally or personally.

The literature on insider/outsider researchers now incorporates the positive elements an "outsider" position can take including objectivity, distance from participants, and theoretical and practical freedom (Merton 1972; Innes 2009). However, this does not address one of the key advantages of "insider" research being that participants are more likely to be more open in what they discuss. In interviews with Black participants where sameness rather than difference was my majority experience, it was clear that this was part of the participant perspectives on the issue. Linking back to the origins of the debate and African-American scholarly views (Innes 2009), some of the Black participants felt that the identity of the researcher would have an impact on how they responded and the subjects they were willing to discuss as demonstrated below.

Because you are from the same background it makes it easier to say the thing, that like sometimes you have almost hidden racism. Nobody is going to understand that unless you

have been there you know like there are some things that you wouldn't feel open in saying because people would think "oh you have got a chip on your shoulder why would you think that?" Of course yes definitely it makes a difference I would have taken part in the interview but my answers would have been different. It's almost like when you have these diversity groups and ultimately the diversity champion is always normally white or you have these groups and people are asking you things and you are guarded you are guarded against what you say (MJ, Civil Servant).

Or another example:

I think it makes a lot of difference to me because I felt here that I could say exactly what I have said today and not feel bad about that because I think I know you would understand or you know you can empathize and I felt comfortable within that because I know that you wouldn't be judging what I have said or making your own assumptions about it whereas I think if it wasn't a Black woman for me I don't think I would I wouldn't have been as open I would have been more reserved because I probably wouldn't have trusted them as much so yeah for me it makes a lot of difference. (Chemma, Community Worker).

This aspect of the debate was not present in the narratives of Deaf participants, but in considering Deaf cultural discourse, it may be premature to conclude that it was not a perspective that they shared. Hearing research with Deaf people in and of itself can create boundaries and limitations that impact on responses. My position as a Black female researcher and specifically a Black female hearing researcher was an integral part of the research as demonstrated by the participant responses discussed. If Deaf participants held similar perspectives about the *importance of experience* of the researcher in enabling wider and deeper responses, it is more likely that they would share this perspective with a Deaf rather than hearing researcher. Using the theoretical framework allows me to recognize that lack of *experience* may create limitations or require further validation and turning to Deaf cultural discourse and the specific history of hearing on Deaf research raises my awareness of the forms these limitations may take.

Fluidity in insider/outsider experiences is now an established element of academic debates (Mullings 1999; Innes 2009; Ochieng 2010; Obasi 2014). While carrying out the research with Black women, I would describe my position as one which was mostly an "insider" position, but this was not a fixed constant position; it was accompanied by moments and situations of difference. For different reasons to Ochieng (2010), I found that I was cast as both "insider" and "outsider" within the same interview. The participant below was reflecting on bereavement and the inadequacies of the allowances made within her workplace, which she felt did not take account to of her cultural bereavement practices.

But things like in the West Indian community if somebody dies they have a dead house, from the minute they die to the minute they are buried and that can be a week. So when you get special leave if it's the mum and dad or close relative you get three days but in reality well you know you need more days.....

Chijioko: So what happens in that 'dead house' then what does that mean?

Well that's when people are allowed to visit the dead house so when my dad died we had to keep food on the go 24 hours a day, alcohol and hospitality so there's always somebody in

so people can pay their respects and when they come they often leave money or they'll bring some kind of food or something like that, to feed other people so it is from when they die to when they're buried and people come round and tell stories. And people just like for a week or so come to the dead house so you see people "oh I've just heard and I've travelled from..." and its things like the funeral, as I understand it in the British culture, you're invited to a funeral but in the West Indian one you can have 300 people because everybody comes. (Sharon, Social Worker).

My ethnic origin is Nigerian and although there are similar aspects of this in relation to cultural burial processes in my own culture, I was not familiar with the name it was given so felt the need to probe deeper. Similarly, many of the participants dipped in and out of patois on occasion or made gestures that were culturally specific to African Caribbean cultures and in a way that there was an expectation that I would understand. Although I am not part of those cultures and so would probably be classed as an outsider by many academic theorists, I am used to hearing patois from within my social circles. As such, I was able to understand the patois that was spoken to me and most of the cultural references that were made. Young Jr. (2004) talks about the advantages outsider status may bring to the research interview when outsiders probe deeper. Had I been an insider on this occasion there may have been no need to probe for an elaboration on the meaning of the "dead house" because of an assumed knowledge. Indeed in some other interviews, there were probably situations where I did not probe and therefore missed the opportunity for elaboration on a specific point. However, it is also clear from some of the responses that the perception of sameness or insider status did facilitate more freedom of expression, trust, and wider discussion than would have occurred in "outsider" research.

5 Connecting to Africanist Sista-Hood in Britain

5.1 Names, Self-Naming, and Naming Identity

The emancipatory elements of Africanist Sista-hood in Britain have built within them recognition of the need to validate counter constructions to that of the majority. In Deaf cultural discourse, Ladd (2003), Padden and Humphries (2005), Hole (2007a), Bahan (2008), and Young and Hunt (2011) have written about the way that majority hearing constructions of Deaf people as disabled are privileged over those articulated by Deaf people themselves. There is also recognition from Collins and Solomos that we need to acknowledge not just the identity that is imposed on us but also that which we choose. Included within this is often the position of resistance and the use of agency against the dominant constructions which in and of itself can lead to mobilization of collectives (Collins and Solomos 2010). None of the participants in the study described themselves or the wider Deaf community as disabled. Their identity was articulated in relation to their culture, their language, and affiliation with other Deaf people as discussed by this participant during the pilot.

I'm a Deaf BSL user part of the Deaf world. culture, language all of that is included that is part of it. Hearing? Not much. Most of my hearing friends are interpreters really so I'm not really hearing led I am more Deaf led. ...My needs my access needs are different from disabled people.who for example may use a wheelchair. Or blind need Braille and they are visible disabilities my needs are not visible. (Erica, Social Worker).

For both participant groups, discussions on identity were interesting and complex and the value in self-naming and validation came through.

Chijioke: What is your ethnic origin?

It depends on the question really; If you mean how I identify or how government label me? If forced to choose I would tick "White British" but if Deaf was there as an option I would choose that. (Mary, Academic).

This response provides a clear link to the work of Lane (2005) and Eckert (2005, 2010), in which they make the case for culturally Deaf people to be recognized as an ethnic group in their own right. Lane provides justification for this perspective by measuring the position of Deaf people or "Deaf-world" against the criteria set out for what constitutes an ethnic group, including issues of language, values, community, history, and art among others (Lane 2005). Interestingly, Mary had no reservations about her nationality being British, which shows there was a clear distinction being made for her own identification as a member of a Deaf ethnic group. Anthias (2010) makes the point that ideational identity can exist alongside legal or judicial identity. Given the power behind anything in the Western world that occupies a legal status, the fight for recognition of Deaf people beyond disability remains an arduous task. Surely, within any emancipatory research, it is perspectives of participants that should be prioritized in how these identities are validated.

Within the interviews and focus groups, there were some discussions of identity and names of some of the Black participants and the way in which the anglicized names they had inherited impacted on their working lives. Within the framework of Africanist Sista-hood, there is recognition of the way in which collective identities of our (an)Sistas can have an impact on our individual identities today. The branding of our enslaved (an)Sistas that took place centuries ago still carries legacies for some Black women in Britain today. This was an issue that was discussed in both focus groups in strikingly similar ways.

Focus group 1

Participant 1: I occasionally get it "oh you didn't sound Black on the phone".

Participant 2: So how does Black sound like?

Participant1: I should have said "a whaa g'on? Ya ready for me come see ya now?" (In patois). (Raucous laughter all round).

Focus Group 2

I used to be a housing officer they would open the door and they would say "oh you don't sound Black on the phone"... I said oh well what do Black people sound like? You

know, they expect you to have this yardy speech or something or speak like a Jamaican you know.

Other similar examples were given by participants where this was either verbalized by service users or colleagues or where the reception received by the Black staff made them think that similar assumptions had taken place. This also provides validation for the Africanist elements within the framework which links back in some way to African heritage or “African descent” as one participant described her ethnic origin. There were instances like those above where Africanist links were implicit, and others where explicit connections were reflected on.

Chijioke: What is your ethnic origin?

For a long time I was African Caribbean and then there was, I go through phases and would just tick African and wouldn't tick the Caribbean bit I was kind of like so distant from that bit. . . . but I have come full circle again and I've gone to African-Caribbean because I think that helps me to understand where I have come from. I think if I just pretend that there isn't a Caribbean element I lose some of my history and my history is that my grandma was dual heritage, . . . my great grandfather was French and you can see through the ages and you can see through the colouring of some of my family members and all of us are not the same skin colour even my brother and sisters we are all different and I think some time you have to, if you don't grab hold of that history that is Caribbean you forget that you have another side to your history and that's the reason. (Marlene, Social Work Manager).

For Deaf participants too, there was recognition of individual and collective identity that existed simultaneously. The participant below when discussing researcher positioning is talking not just of her own identity, but an identity linking back to a Deaf history of oppression exclusion and discrimination. Again, the framework points the analysis in the direction of historical significances, but it is the theoretical alliance with Deaf cultural discourse that provides the detail and implication of that specific Deaf history and its links to the present day.

The Deaf community through history experience discrimination, for example, Milan-discrimination (The Milan congress of 1880 is well known in Deaf communities for having had a detrimental impact on the education of Deaf children because of the decision that was made to ban sign language in deaf schools (See Ladd 2003 for comprehensive review).), cochlear implants- discrimination. Because society and governments only respect us for research, research what for? Research **on** me for your benefit then future what? Eradicate Deaf for the philosophy utilitarianism- for the benefit of the greater good compared to the few. The Deaf community is small and hearing society is the majority so that's why. (Mary Academic).

From these very interesting, complex, and history-steeped responses, it becomes clear that, as individuals, it is not always possible to be or be seen as separate from our histories, which is an important factor regularly overshadowed by post-structuralist and post-race perspectives currently flooding academic debates. Although the concept of agency should not be excluded from any academic debates about collectivity and connectivity in identity, those histories will still have an impact on our everyday lives regardless of the extent to which they are

acknowledged. Those impacts are not always constant and vary to differing degrees and in differing situations.

5.2 Space and Place in Africanist Sista-Hood

Atewologon and Singh (2010), in their study of black professionals' workplace identity, talk of the way participants recognized a differentiation between a "black British" and "black in Britain" identity. This was also an issue that was echoed by participants in one of the focus groups where the general view was expressed by the participant below:

I think there is a scale in terms of you can be Black and have an English accent and you can be Black and have an African accent and the English accent will be treated better than the African accent. (Focus Group 2).

Similar issues came out in the analysis of the participants individual interviews, three of which were born in Africa, and of those, two of them were born in countries subject to the apartheid system. When asked about their identity, their view included the base line position of being considered as a human. Though interviewed separately and unknown to each other, part of their responses on the issue provided quite similar perspectives:

Sometimes there have been times when I am filling forms in I will actually leave it blank or sometimes I have been naughty enough to write human being. (Makosi, Social Worker).

Or another participant

I just identify myself as a person really, I would say just as a human being who has every right to be here! (Jain, Support Worker).

Within the framework of Africanist Sista-hood **in Britain**, there is the recognition of the need to be flexible enough in moving away from the notion of Britishness which for some is unobtainable and for others is not an aspect of their identity they readily wish to showcase. At the basic level, as Black women, we all have in common the experience of being Black women "in Britain," while recognizing the diversity of experiences this encompasses, the focus becomes one of location rather nationality. This provides a further welcome divergence from the terminology of Black British feminism and the Britishness this encompasses.

The framework recognizes the way in which as Black women our spaces are heavily regulated and policed. Within the narratives, there was evidence of different coping strategies employed to deal with this, some of which were influenced by some of the symbiotic relationships related to "race," gender, and the social spaces occupied by Deaf people.

Three of the five Deaf participants in the study talked in detail about the working relationship with other hearing professionals who can sign. A central theme within

the Africanist Sista-hood framework is the concept of *knowing without knowing* taken from Reynold's analysis of Collins' work on Black feminist thought. For the three Deaf participants, this was a significant issue that seemed to cause them problems in the workplace on a regular basis. The hearing signing colleagues who were afforded this position of knowing without knowing were sometimes seen as the instigators as in the first example provided below. But in others examples, the issue was that the hearing signing colleagues were seen by the wider organization to have *knowledge* of Deaf people, their language and/or culture, and that they were the preferable source through which to access this *knowledge* even where the Deaf participant was the obvious person to contact as in the second example provided below.

Four of them [hearing, signing colleagues] meetings, networking no Deaf involvement. . . . Them represent us? No thank you! You have to be Deaf. Must Deaf because of experience. We know what we want. Networking is brilliant but bring Deaf or Deaf go by themselves with interpreter. . . . They don't share the information with us because we are second class. . . . I wanted to say if it wasn't for us Deaf you wouldn't have those brilliant jobs. . . . They are climbing their ladders on our backs! (Janet, Academic).

One of the participants here discusses the way in which her efforts to tackle a personal issue with the human resources section was discussed with another hearing, signing colleague and therefore circumventing the need for direct contact.

They should involve Deaf directly. For example I went to see Susan [a hearing HR representative] for something. . . . she came back asked Tammy [a hearing signing colleague] about it. I ask her why not ask Susan to ask me herself? She said it was to save time so (Facial expression what can I do?). . . . she should ask them to ask me. (Carol, Academic).

Whatever the case, these approaches leave the Deaf person feeling devalued in terms of their professional status but also further strengthens the power relationships that exist in the workplace between signing hearing people and their Deaf colleagues. Hearing signing colleagues by accepting this approach act as enablers to the circumvention then either wittingly or unwittingly become gatekeepers to the information that should rightfully be gained or passed on via direct access to the Deaf person themselves. A further issue is whether these power advantages are acknowledged, challenged, or perpetuated by the hearing colleagues in question.

Issues regarding physical spaces occupied by Black women in the workplace were also discussed in some of the interviews and focus groups. The examples below, however, demonstrate the ways in which the pressure of our hyper-visibility can force us to self-manage it. This participant provides an explanation of the reasons and the manner in which she tries to self-regulate her position of hyper-visibility.

When Rena (Black participant) comes to my organization and Pat (Black participant) I just shush them straight away. . . . I do it because I don't want to be looked at or be noticed to be honest, and I put myself on mute I say it all the time when I go to work I put myself on mute I can't be who I am. (Focus group 2).

I have written in an earlier paper (Obasi 2013) about the ways in which hyper-visibility and invisibility can exist in the same person, and within the study a participant summarized the issues very well in relation to the collective identity of Black people in her community. Having contributed to discussion about the frustration of trying to progress services for Black community members her conclusion was as follows:

I always say that as the Black community we are the visible invisibles, we are visible by our skin colour but invisible when it comes to services and that's a real battle (Focus Group 2).

6 Conclusions and Future Directions

Creswell (2013) and Liamputtong (2010) recognize that the position of the researcher has an impact on every stage of the research process, and the same is recognized within this study. My own personal position as a researcher had an impact on what I chose to study, how I chose to study it, who I chose to study it with, and the framework I chose to use. From the contributions of the participants, it seems that my personal and professional identity also had an impact on the interactions that occurred. The framework of Africanist Sista-hood in Britain, while building on existing works, helps create a deep level of analysis of the data when connections are made to collective, historical, and individual experiences. In working in collaboration with Deaf cultural discourse with its attempts to foreground counter constructions of language, culture, and or ethnicity, I also leave space for further contributions from others researching with other social groups. Working with other social groups may necessitate different theoretical alliances and emancipatory approaches.

Johnson-Bailey (1999, p. 669), when carrying out research with other Black women, acknowledges some of the dividing lines between researcher and researched, but concludes that "there were many more times when the experience of a Black woman interviewing a Black woman was advantageous." From the data collected in my own study, it would also appear that this was the majority view both of the participants as well as myself as the researcher.

Deaf women, for the most part, also expressed a preference for Deaf researchers as well as setting parameters within which hearing researchers can work. As outsider hearing researchers, there are mitigations that can be introduced such as interviewing in sign language and incorporating participants in shaping the research, but the position of "partial knowledge" or "professional knowledge" held by hearing signing researchers can be a double-edged sword and one that has been used against Deaf people in the form of oppression and exploitation. It is difficult to see a way in which our identity as hearing researchers can have the same majority advantageous position which would be gained from Deaf with Deaf research.

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Researcher Positionality in Cross-Cultural and Sensitive Research

92

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Contents

1	Introduction	1602
2	Researcher Positionality	1603
3	Placing Issues in Cross-Cultural and Sensitive Research	1603
3.1	Gender Issues	1604
3.2	Age Issues	1607

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3.3	Race, Culture, and Ethnicity Issues	1608
3.4	Social Class Issues	1610
3.5	Shared Experiences	1612
4	Conclusion and Future Directions	1613
	References	1613

Abstract

The status of the insider and outsider is an important concept for cross-cultural and sensitive research. In recent years, the concept of placement of the researcher has received much attention. Until a few generations ago, researchers who shared the same cultural, social, and linguistic background with those of the research participants mainly conducted research. However, over the last two decades, we have started to witness researchers who have different characteristics to that of the research participants conduct research in health and social sciences. In current times, this has led to the debates of insider versus outsider status of the researchers, as the way research participants “place” the researchers, and vice versa, is vital for the success of any research. In this chapter, we shall introduce the concept of researcher positionality. We will look at the debates on researcher positionality in cross-cultural and sensitive research and discuss “placing” issues such as gender, age, culture and ethnicity, social class, and shared experiences.

Keywords

Sensitive research · Insider · Outsider · Placing issues · Positionality

1 Introduction

In research, the opinions, values, beliefs, and social background of researcher influence him/her in the research process, shaping each methodological and analytical decision he or she makes. This chapter introduces the concept of researcher positionality and its potential influence on the research process making a case for all researchers to consider the importance of researcher positionality in their research.

Research, according to England (1994, p. 82), “is a process, not just a product.” Research signifies a mutual space, shaped by both researcher and participants (England 1994). Hence, their identities have the potential to influence the entire research process. Identities are established through our perceptions, not only of others, but also by the ways we expect others to perceive us (Bourke 2014). Kezar (2002, p. 96) states: “Within positionality theory, it is acknowledged that people have multiple overlapping identities. Thus, people make meaning from various aspects of their identity...” Additionally, researchers’ biases define the research process. Thus, by identifying their own biases, researchers can gain insight into their approach towards research settings, members of particular groups, and their relationship with research participants. This has led to debates on the insider versus outsider status of the researcher in recent years, especially in cross-cultural and sensitive research (Ergun and Erdemir 2010; Liamputtong 2010; Edmonds-Cady 2012).

In this chapter, we first introduce the concept of researcher positionality and discuss the relationship of researcher positionality with reflexivity. Thereafter, we provide detailed explanation with examples from our research and from other researchers on insider versus outsider perspectives on the impact of gender, age, culture and ethnicity, social class, and shared/unshared experiences on the research process and research outcome(s).

2 Researcher Positionality

The term positionality describes an individual's view and the position he/she has chosen to adopt in relation to a research task (Savin-Baden and Major 2013). These are often shaped by political allegiance, religious faith, gender, sexuality, geographical location, race, culture, ethnicity, social class, age, linguistic tradition, and so on (Sikes 2004). Positionality reflects the position the researcher has taken *within* a given research study (see also ► Chaps. 91, “Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women,” and ► 125, “Police Research and Public Health”). Some aspects of positionality are fixed such as gender and race while others are subjective such as personal experiences.

Positionality requires the researcher to acknowledge and locate their views, values, and beliefs in relation to the research process. Self-reflection is a mandatory ongoing process in any research project as it gives the researcher the ability to identify, construct, and critique their position within the research process. Reflexivity, the concept that researchers should acknowledge and disclose their own selves in the research, seeking to understand their part in it, or influence on the research (Cohen et al. 2011, p. 225), informs positionality. It is a self-reflection on how their views and position might have influenced the research design, the research process, and interpretation of research findings.

Savin-Baden and Major (2013, pp. 71–73) identify three ways of researchers accomplishing positionality. Firstly, researchers locate themselves in relation to the subject, i.e., acknowledging personal positions that have the potential to influence the research. Secondly, they situate themselves in relation to the participants, i.e., how the researchers view themselves, and how others view them. Thirdly, they locate themselves in relation to the research context and the research process, i.e., acknowledging that the research will be influenced by the research context.

3 Placing Issues in Cross-Cultural and Sensitive Research

The way research participant “place” the researchers, and vice versa, is vital for the success of any research (Al-Makhamreh and Lewando-Hundt 2008; Ramji 2008; Wegener 2014; Berger 2015; Hayfield and Huxley 2015). Here, we will discuss the positionality of researcher as perceived by the research participants (Liamputtong 2007, 2010). There are various “placing” issues such as gender, age, culture and ethnicity, social class, and other identities that have a significant impact on the

research process and the research outcome(s) (Breen 2007; Al-Makhamreh and Lewando-Hundt 2008; Ramji 2008; Maylor 2009; Al-Natour 2011; Manohar 2013; Wegener 2014; Berger 2015; Hayfield and Huxley 2015; Suwankhong and Liamputtong 2015). Such “placing” issues will be discussed in following sections.

3.1 Gender Issues

Considerations on the influence of gender in fieldwork, particularly by researchers of gender opposite to that of participants, have highlighted the essential role of gender in research depending on the situation (Al-Makhamreh and Lewando-Hundt 2008; Enguix 2012; Takeda 2012; Pante 2014). Such contextual and situational appreciation of the impact of gender in research creates a dynamic perspective of how gender interacts with other social and cultural aspects related to research (Galam 2015).

In our previous research (Arora et al. 2012b, 2014), we noted that migrant mothers whose first language was not English were not comfortable talking about sensitive topics such as breastfeeding and birth experiences to male researchers. We also noted that women from culturally and linguistically diverse backgrounds were uncomfortable talking about breastfeeding in public as they considered the discussion about breast and/or breastfeeding to be of sexual nature. Furthermore, we noted that women were shy talking about breastfeeding issues such as latchment, sore and/or cracked nipples for similar reasons. They particularly felt uncomfortable talking about female issues to a stranger (male researcher) and felt they were only comfortable to their husband and not other men in general. One of the research participants in our study pointed out:

I just feel uncomfortable talking about breasts to men except if it's my husband. This is something too personal and sexual for me. . .

In order, to make the interviewees more comfortable, we ensured that both male and female researcher were present at the time of the interview. This helped the interviewee to be at ease, as they could feel better connected to female researchers.

In our research with new mothers, women were comfortable talking about the birth experiences and breastfeeding issues to other women in general. This is because they felt women share the similar body anatomy and could relate to the experiences better. Pingol (2001), in her research on migrant women conducted interviews of their husbands, noted that gender had no effect on her relationship with participants. However, she recognized that female participants were more comfortable in discussing their sexual matters since she was of the same gender.

Interestingly, in our research with English-speaking mothers (Arora et al. 2012a), women were very comfortable talking about breastfeeding and other female matters with male researchers. Our reflections from our previous research highlighted that it is more difficult to conduct cross-gender research with new migrant women. However, if migrants have lived in western countries for long or if they are migrants from English-speaking countries, it is much easier to build rapport and collect good quality data.

Al-Makhamreh and Lewando-Hundt (2008, p. 11) contend that “cultural and social norms construct certain gender expectations that researchers can negotiate and act within.” In a sociocultural context, gender is particularly important due to the existence of sexual boundaries and gender domains. Therefore, in all research methods and processes, gender needs consideration primarily because cultural and social traditions require certain expectations from researchers and participants in regard to gender (Järviuoma et al. 2004). Researcher of same gender may encourage the interviewees to be more open about their feelings and thoughts since they may share common assumptions and experiences (Riessman 1994; Liamputtong 2010; Suwankhong and Liamputtong 2015). Therefore, the data gathered by female researchers from female participants may well be different from that collected by male researchers and vice versa. Gill and Maclean (2011) suggest that when the researcher and participant are of same gender and culture, the communication is easier because they can clearly appreciate the mutual aspect of gender and culture, thereby the produced data is more sensibly interpreted. In our research with Mandarin-speaking migrant women we had similar reflections (Arora et al. 2012b). In particular, we noted that Mandarin-speaking women were very appreciative that female Mandarin-speaking researchers were keen to speak to them over the phone, in their own language, give infant feeding advice that was culturally appropriate, and took the time out of their busy schedules for a home-visit. We also noted that the quality of these interview data was excellent as women shared personal insights of their routine lives.

Gender has been the subject of intense debate among feminist researchers. The position and role of men as a researcher has always been a topic of debate in the domain of feminist research. It is due to the fact that men’s status in feminism is still marginalized no matter how much they are committed to women’s problems and concerns. Many feminists exclude men from feminist research on the grounds that men cannot experience the world in the same way as women. Although it is true that men cannot experience women’s problems and concerns in the same way as women, it does not restrict men to make a contribution to feminist research. Feminist researchers feel that female interviewers best interview women respondents. In our breastfeeding research in Sydney, Australia, we noted that female interviewees were willing to discuss their personal lives with female researchers. One of our respondents stated: “Of course I would prefer to talk to a woman because she would understand me. I would not be embarrassed to talk to her about how I feel.” Al-Makhamreh and Lewando-Hundt (2008) noted that in spite of being the same-gender, Al-Makhamreh had to consider the respondents’ social constructions of gender, employing “informal but respectful nomenclature,” for example, referring to respondents as “mother of Sahar” or “father of Jamal” rather than their first names (p. 18). In our research with Arabic migrant women in Australia, we also employed informal respectful nomenclature such as “mother of Mohammed” when male researchers interviewed female Arabic migrants on oral health. Also, we used terms such as “sister” to refer to the respondents since in Arab society it is a culturally acceptable method for “cross-gender interactions” and “a way for a male to frame interaction with a woman in a nonsexual way.”

In perspective of a male researcher undertaking research within gender-segregated communities, Abdi Kusow (2003), a Somali male researcher whose research involved Somali migrant community in Canada, experienced difficulty in accessing as well as meaningfully interacting with the female participants. He contends that “in such social arrangements, cultural or racial differences or similarities do not determine insider or outsider status; the social organisation of gender does. What this situation suggests is that a Western, outsider, female ethnographer may have better access than would I as a native male ethnographer” (p. 597). He summarizes his dilemma as follows:

I was able to talk to several Somali female students at the local universities, but beyond them, finding access to female participants remained a daunting experience. In the Somali social context, one cannot simply call a female participant for an appointment or go to her house without the assistance of a male relative, for one must avoid any suggestion of impropriety or other misunderstandings. If the woman is married, the situation is even more complicated. Married women cannot, at least officially, associate with men other than their husbands or relatives regardless of the circumstances. (p. 597)

Similarly, Brandes (2008) in his cross-gender research in Andalusia, where strict gender domains existed, had to gain access to female participants through their husbands. Apart from gaining access to the participants, the issue of building rapport is critical in cross-gender research as it is noted that often men are more reluctant to open up to a female researcher because they are less used to being questioned by women, and they do not expect women to understand their experiences.

It is believed that sharing the same gender can have multiple advantages for both the interviewer and interviewee, such as reducing the social distance, facilitating communication, and providing a positive and beneficial experience (Finch 1993). In her research on breast cancer conducted by Dusanee Suwankhong and Pranee Liamputtong in Australia (Suwankhong and Liamputtong 2015), they were recognized as an insider by the research participants as they shared the same gender. One of her research participant said:

I sometimes check my breasts like this [her hand press on her breasts when showering]. I want to check if there is no lump or anything like that . . . abnormal thing. If there is something wrong I can go to the doctor early. Mine is possibly small size, hah (her face turned red and still holding her breasts). See, if you are a male interviewer, I would not touch mine and show you like this. I would feel too embarrassed! But you are a woman. I am not too shy to talk about this thing and can show my breast to you as I should, why not.

On the other hand, Kusek and Smiley (2014, p. 160) noted that in spite of their cross-gender apprehensions, the male participants were “approachable, friendly, and eager to share their stories.” In their opinion, being in a position of female researcher might be beneficial, as male participants were not only boasting about their professional successes but also shared personal problems probably to gain empathy, a

behavior which would have been less verbalized in case of male researcher. However, Kusek and Smiley also noticed that their gender made the female respondents more comfortable and acquire easy access to their homes which they felt male researchers would not have necessarily gained. They certainly experienced reluctance to research participation, but gender had no link to it.

3.2 Age Issues

Besides gender, age of researcher also influences the research process, particularly in establishing relationship and trust. In several cultures across the world, older age implies respect. Therefore, older participants might not extend due respect to younger researchers which can jeopardize the quality of research findings. For example, particularly in a South Asian rural society perspective, a young unmarried female researcher would find it difficult to engage and establish rapport with older married female and male participants. Stiedenroth (2014, p. 84) in her research in Pakistani rural communities writes:

I experienced that my age (22 and 24 years old during each fieldwork period respectively) and my status (unmarried and childless) were more central to my positionality than being a western foreigner, at least in respect to contact with men in the field.

On the other hand, Suwankhong and Liamputtong (2015) highlight the importance of being recognized as an insider in research rather than the influence of age. They highlight that a young researcher would be seen as a family member and the access to participants and building trust with the participants becomes easier if accepted as an insider.

The age of researcher is crucial in a sense that it creates a learning sensitivity to difference in expression of thoughts based on the age of participants. Generally speaking, younger participants share a wealth of lived experiences with young researchers. However, older participants often do not share a great deal of information with younger researchers. This may be due to the fact that older research participants feel a lack of similar shared experiences with younger researchers. Underwood et al. (2010) noted that a young, novice researcher (aged between 28 and 30 years at the time of research) observed that younger participants provided detailed information during interviews whereas older interviewees responded with short answers and made comments that suggested either the questions were not relevant to them or they did not understand the interviewer's questions and perspective. In our breastfeeding research in Sydney, Australia, we had a similar experience. One of the interviewer/researcher said:

Most study participants were 25–35 years old, (and) I am in that age range, so I felt I could relate to them from that standpoint.

In one of our current research projects with older Australians (70+ years), we faced many issues with recruitment of study participants. We believe that one of the key reasons for difficulties in recruitment is that the researcher recruiting the study participants is only a 30-year-old young woman. Further, we noted that the study participants, particularly men, did not feel connected to the younger researcher as they believed that the researcher would not understand their perspective on health issues. We noted that not only were the study participants harder to recruit but they did not participate well in the research process. The interview responses were relatively short, and it made the researcher feel that she had not explained herself well or she was not a good researcher. One of our research participants said: “I feel I haven’t explained myself very well. Maybe I’m not grasping what you want.”

Interestingly, older migrant men in our current work in Sydney, Australia, treated the interviewer not only as a researcher or a young woman, but as a young person who can be given pieces of advice in life. The female researcher was met with paternalistic treatment wherein the researcher was treated as a daughter.

Chawla (2006) in her ethnographic research on Hindu marriages involving Indian women discusses about “shifting subjective experiences,” which she experienced in the field. She states that researcher positionality is controlled by participants. Since her research participants included participants from different age groups, her experience reformed as per participants’ perceptions. In her words:

With the young group, I was accorded the role of native, thus hyper-eligible. With the middle group, I was adjusted: first as an insider, and later as an outsider and stranger. With the older group, I was ‘another’, a comfortable stranger, and, in more ways than one, the professional stranger of ethnographic work. Ultimately, I had to experience these eligibilities to reflect on and converse with their life-histories. . . . These eligibilities originated from my single status and not from my displaced or rooted ethnic identities. (Chawla 2006, p. 13)

In research projects where there is a relatively larger age difference between the participants, choosing appropriate questions to elicit meaningful information can be a daunting task. It is a norm that the questions used should be of equal relevance to all study participants. However, it has been proved that the researcher needs to be on the same “wavelength” as the participants especially in respect to their age. One way to minimize the impact of researcher biases is to conduct focus groups because they facilitate the undertaking of unstructured interviews, provide more freedom to the study participants, and allow the group to take control of the interview (Liamputtong 2013).

3.3 Race, Culture, and Ethnicity Issues

It has been suggested in the literature that researchers who undertake cross-cultural research should be an “insider,” i.e., they should share the same social, cultural, and linguistic characteristics with the research participants (Merriam et al. 2001;

Al-Makhamreh and Lewando-Hundt 2008; Ergun and Erdemir 2010; Liamputtong 2010). This is what Ramji (2008) refers to as cultural commonality.

According to Banks (1998), there are two main types of researchers in cross-cultural research – cultural insiders and outsiders. Cultural insiders have commonality with the research participants as they share the same social background, culture, and language. Banks (1998) notes that being a cultural insider is the best approach for successful fieldwork. It is often argued that researchers sharing same cultural characteristics as their participants are in a better position to discover research ideas, arguments, and opinions. This is because they are seen as a “legitimate member of the community” (Liamputtong 2010) and provide better insights when describing the social and cultural characteristics of the participants with whom they undertake research (Tillman 2002; Liamputtong 2010). Cultural outsiders refer to the outsider researcher who enters a local area to conduct research. They hold different views, values, beliefs, and knowledge from the community where they undertake the research.

Cultural insiders may be able to conduct research “in a more sensitive and a responsible manner” than outsiders (Bishop 2008, p. 148). Due to cultural commonalities, they are better placed to gain the trust of the research participants and build relationships (Shariff 2014). This can often reduce the difficulties in building rapport with the research participants. One of the Thai-speaking respondents from Suwankhong and Liamputtong’s research in Australia (2015) remarked that: “I am very happy to help. . . . at least I can share my story with others. . . I always like to support other Thai people when I can. . .” Further, in their research with traditional healers in Thailand, Suwankhong was seen as a cultural insider as she spent most of her life in a Thai communal environment and showed the same norms as that of the local community. They highlight that being accepted as a cultural insider is crucial in cultural research that allowed to cultivate a trusting relationship with the participants. Liamputtong (2010) contends that one of the key reasons to be seen as an “insider” by the research participants in cross-cultural research is the use of same language. In their work in Thailand and Australia with Thai women, they used Thai language and were able to avoid difficulties regarding language issues. They further highlight that having a shared ethnic identity helps in being recognized as a cultural insider and build a trusting relationship.

In our research with Indian migrants in Sydney, we noted that being a cultural insider helped facilitate the interviews due to the relationship of trust between the research participants and the interviewer. Families were able to share their personal stories on the migration process as researcher and the research participant spoke the same language.

However, cultural outsiders may also be able to get deeper understanding and explanations of a phenomenon under investigation (Al-Makhamreh and Lewando-Hundt 2008; Liamputtong 2010). This is because they may not know much about the lives of the research participants and therefore may want to get a closer and a detailed look into what is being researched. In fact, Merriam et al. (2001, p. 411) contend that “insiders have been accused of being inherently biased, and too close to the culture to be curious enough to raise provocative

questions.” To them, “the insider’s strengths become the outsider’s weaknesses and vice-versa” (p. 411).

Additionally, in regard to “insider perspective,” a term called “diversity in proximity” has been used (Ganga and Scott 2006). It illustrates that as an insider, the researcher is better able to recognize not only the ties that bind him/her and participants but also the social fissures that divide them (Ganga and Scott 2006). Insider or outsider positionality can influence the researcher’s objectivity, and furthermore can influence the social dynamics of interviews. Martiniello (cited in Bousetta 1997, p. 6) cautions:

During data collection, for example, an ethnic background can be very helpful. Ethnic researchers can have privileged relations with immigrant groups, which can facilitate access to the field. Similar advantages arise from familiarity with the languages and the physical space of the researched group. On the other hand, such closeness between a researcher and his/her subject can also harm the research process.

In certain research scenarios, race of the researcher plays a very influential role in participant interviewing. For instance, Fletcher (2014) points out that in cross-cultural research, the ethnic minority participants often distrust the white researchers as they are considered as cultural outsiders. One of his participants said: “For most you’re fine. Some probably won’t ever speak to you. They’re (the British Asians) happy to train and play alongside you, but they probably won’t sit and talk to you” (p. 252). On the other hand, Pasquini and Olaniyan (2004), in their research involving Nigerian farmers, experienced that Pasquini being a white researcher enjoyed a favorable position whereas Olaniyan being a local Nigerian but of different tribe made him an outsider. A Nigerian would prefer a white person over a fellow “black” person, probably due to perception that white people are wealthier and/or even superior. In this case, Pasquini was the white person who was held in high regard and respected due to her race. Additionally, the farmers, based on their previous experience with white people, found them to be trustworthy, organized, and influential with government authorities in order to get help for them. This might be another reason due to which the farmers were forthcoming in regard to sharing their opinions and thoughts with her. Moreover, Nigerians consider white people as guests and since she was interacting with them, the farmers might have felt obligated to respond. Africans have a tradition to treat well the foreign as well as African guests, as they feel something good might come of it. Olaniyan, on the other hand, was a Nigerian, but of a different tribe which did not make him an “outsider” per se but was still not considered one of them. The point to consider in this research-participant interaction is that despite of being from a different tribe, Olaniyan, due to the common language, was able to gain acceptance and trust of the farmers, and served as an interpreter between “madam” and farmers.

3.4 Social Class Issues

In addition to the issues discussed earlier, differences in social class of the researcher and participants also pose as barrier to the research process (Rashid 2007; Ramji

2008). For example, it is believed that if researcher is of a middle-class background, differences of authority and privilege within a research setting could not only negatively affect the marginalized groups but such researchers may also be unable to adequately comprehend or represent the lives of marginalized groups (Mellor et al. 2014). Mellor et al. (2014) further highlight that despite enough research evidence, there seems to remain anecdotal preferences among class researchers for class matching, particularly when research involves working-class participants. This preference of class matching is likely to be guided by the assumption that if middle-class researcher interviews the marginalized groups, the differences in the power could potentially harm the marginalized groups. Further, there has been criticism that middle-class researchers may not understand the lives of the marginalized groups. In our research with vulnerable families in Australia, we did not experience that class of the researcher influenced the research process in any way. In fact, in the focus group discussions the research participants felt quite privileged to share their personal stories with medical researchers (who they considered as health and education idols).

Mellor and her research team (2014) felt that middle-class students were more open and able to challenge their representations as privileged when interviewed by working-class researchers. One of the respondents explained the sacrifices which his parents had to make to send him to a prestigious school; the authors felt that such response would not have been received if that student was interviewed by a fellow middle-class researcher and in fact he would have highlighted his privileges rather than his parent's sacrifices. Nevertheless, at many times, it was observed that working-class interviewers shared a strong affiliation with working-class interviewees. The researchers felt like "insiders" and students openly discussed their difficult backgrounds and current circumstances without any shame or prejudice.

Hoskins (2015), in her research relating to researcher positionality involving female professors, contends that her social class, gender, age, and ethnicity all influenced the quality of interviews and the research process itself. She was able to establish strong connections with several participants from working-class backgrounds as she could relate to some of their experiences and instances of feeling as an outsider at the workplace.

In some religious communities, caste plays a major role to determine the acceptability of researcher. Ramji (2008), who herself is Hindu, conducted research within London's Hindu Gujarati community. She experienced being questioned about whether she belonged to the same or a higher caste as to the respondents, the reason primarily being that caste is a crucial factor in Gujarati Hindus. Ramji asserts that "lower caste Gujaratis were somehow thought to be lesser Hindus. This is indicative of the inter-connected relationship between caste status and religion in Indian culture: a similar caste Gujarati would share a similar perception of Hinduism" (p. 106). Also, her linguistic accent was judged to be non-Londoner while London was seen as "a natural place" for Gujarati Hindu identity, which made Ramji an outsider. However, this "outsider" status had a positive implication in her research process since some female respondents were able to openly discuss their lives without the prejudice of offending other community members.

To say the least, many researchers (see Rashid 2007) are of the opinion that social-class differences in the research process are a reality, which enable respondents to draw unrealistic assumptions towards the researchers. However, the researchers can position themselves and adopt specific interviewing methods to markedly minimize the gap between them and the respondents.

3.5 Shared Experiences

The way the participants place the researchers inside or outside the shared experiences is another important placing issue. In their research on working with their own communities, Yakushko et al. (2011) reflected on their personal experiences and highlighted that belonging to the same community and having shared similar life experiences helped them undertake high quality research in migrant communities. Similarly, Egharevba (2001) described that she shared similar skin color with the participants that had a positive impact on the research. In her research, she described that many participants told her that they would not have felt comfortable discussing their views and experiences on racism with a white researcher. Egharevba concluded:

What they saw in me was another minority person who was living in a racist country, a commonality which made them feel less vulnerable than they would have felt with a white researcher. This shared experience transcended many of the apparent differences between us. (p. 239)

As part of recent research we conducted in Greater Western Sydney, Australia, with migrant Asian parents on child oral health (Arora et al. 2012b, 2014), we were able to get personal insights into the health behavior patterns of their children. Mothers in the study said that they felt more comfortable to talk about the diet practices of their children with us who were from Asian ethnic background and had many shared experiences regarding dietary practices with them. One mother from our study said:

I don't like to give him (the child) tap water. You (the researcher) are Chinese, so you know what I mean. Chinese avoid tap water as we know water quality is poor in China. I really haven't changed my opinion on it in Australia.

However, in our previous research with Australian women on infant feeding practices (Arora et al. 2012a), we provide an interesting example of shared experiences between the researchers and our research participants. We anticipated that the interviewer characteristic (male researcher) might be a problematic issue during the research process. The literature suggests that male researchers conducting research on women's health may be challenging due to the fact that men's status in feminism

is marginalized no matter how committed they are towards women's problems. Further, we anticipated that a researcher who did not share the same experiences (without children) with the research participants (with children) may compromise the quality of the interviews. On the contrary, our experiences on researching with women on infant feeding experiences brought authenticity and a different dimension in breastfeeding research. Interestingly, women in our recent work highlighted that they were able to share their personal stories as families had built rapport with the research team. One participant said:

We have known you for almost a year since she (the child) was born. I don't mind talking about my experiences with you. You are a health professional and I don't think about it in a sexual way although we talk about breastfeeding.

4 Conclusion and Future Directions

In his recent book, Cresswell and Poth (2017) acknowledges that the position of researcher has an impact on the research process and research outcomes. The case examples presented in this chapter recognize the importance of insider/outsider issues in cross-cultural and sensitive research. This is particularly important in a country such as Australia, which has culturally and linguistically diverse population and may be vast differences in social class. Hence, it is most likely that health and social science researchers will work with research participants from different socio-cultural backgrounds and therefore researchers need to acknowledge the importance of positionality in terms of wide-ranging placing issues such as gender, age, ethnicity, social class, and shared experiences.

We would encourage readers to ascertain their positionality and think about their own status carefully before commencement of the research process, and continue to reflect on it throughout the data collection process. In particular, they should be aware of their position among those being researched, how they conduct research, and their understanding of the phenomenon and/or context being examined. The insider and outsider status of the researcher may shift during the course of research project, and researchers will need to clarify and maintain their position during the entire course of cross-cultural and sensitive research.

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Considerations About Translation: Strategies About Frontiers

93

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Contents

1	Introduction	1618
2	A Brief Review of Studies on Translation	1619
2.1	Lexical Issues	1619
2.2	Syntactic and Semantic Issues	1620
2.3	Ethical Issues	1620
3	Current Situation	1621
4	Translation	1622
5	Linguistic Treatment	1623
6	Addressing the Task of Translation	1624
7	Difficulties, Strategies, and Rules in Translation	1626
8	Translation Competence	1629
9	Implicit Ethical Issues	1630
10	Conclusion and Future Directions	1632
	References	1635

Abstract

The translation of any text focuses action and attention on the transference of a source language into a target language. It entails different methodological issues that range from linguistic treatment, grammatical issues of the languages considered, lexical issues and how to approach them, space and time considerations in a given textual construction, implied ethical questions, and so on. The approach to such issues varies from one translator to another. While some look for lexicographic patterns between the original text and its translation, others seek to convey the sense of the original text in the contexts of translation. Against this background, this chapter reviews some theoretical questions underpinning methodological approaches and those approaches as used in translation, along with

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normative, linguistic, and ethical issues, concluding with a reflection about translation in cross-cultural research. For such purpose, this chapter draws on a bibliographic review and the experiences of researchers who translate or have translated different types of texts – mainly written ones – in a nonprofessional manner.

Keywords

Translation · Lexicographic pattern · Methodological approach · Linguistic treatment · Grammatical issue · Lexical issue · Space and time consideration · Theoretical question · Internationalization of English

1 Introduction

Communication is a phenomenon inherent in human nature, and, as such, it entails a shared experience – a bond. In reviewing the polysemic character of the term, Rizo García (2012, p. 22) provides a general definition of communication as “a basic process for the construction of life in society, as a mechanism that produces senses, activates dialogue and coexistence between social subjects.” Communication allows the social fabric to be conceived as a network of interactions and is interwoven with culture(s) and identity(ies).

Within this framework, it can be stated that culture – seen as a network of meanings – is closely related to identity(ies), which evidence(s) the subjective processing of cultural matrices. Both culture and identity are connected with the notion of frontier – a diffuse concept – that is characterized by its duplicity as an object/concept and as a concept/metaphor. Thus, there are on the one hand physical, territorial frontiers, and, on the other, cultural, symbolic ones (Grimson 2011) (Grimson (2011) conceives cultural frontiers as significance regimes that are distinguished and perceived by their own participants.).

Against this backdrop, translation is the task of transferring a text from the source language to the target language, which also involves the adoption of a specific attitude toward certain frontiers. In this sense, it is worth noting that fidelity to the original played a central role in translation for a long time, until it was replaced by an equivalence-oriented approach (Snell-Hornby 1990, p. 80, cited in Carbonell 1996, p. 143). Hence, the subject matter of translation studies has gradually shifted toward prioritizing the communicative aspect of translation (Carbonell 1996).

Thus, in the management of the everyday world through language, whether the target text becomes part of the canon of the target culture or emphasizes its differences depends on the choice made by the translator. This also brings to the fore other issues associated with the translation task, such as the position to be adopted with respect to textual-, cultural-, and identity-related polyphony, that is, ideological issues and issues relating to disparities between the different narratives and cultural agency.

In this chapter, I review some theoretical questions underpinning methodological approaches and those approaches as used in translation, along with normative,

linguistic, and ethical issues concluding with a reflection about translation in cross-cultural research. For such purpose, this chapter draws on a bibliographic review and the experiences of researchers who translate or have translated different types of texts – mainly written ones – in a nonprofessional manner.

2 A Brief Review of Studies on Translation

2.1 Lexical Issues

Vázquez, Fernández and Martí (2000) present a classification of verb-centered mismatches between Spanish and English. Such classification is based on a proposal for lexical representation of linguistic knowledge, thus falling within the scope of lexical semantics. The authors' proposal relies on a model for lexical description that considers meaning components, event structure and diathesis alternations. The paper describes how these elements allow creating a framework for the analysis of mismatches. Along the same lines, the authors suggest how to use conceptual transfer to cope with these mismatches in a Machine Translation system.

Martínez-Melis (2008) examines the translation of the Heart Sutra, a Buddhist text of the prajñaparamita sutra literature, which has been highly influential in Chinese culture since it was first translated in the fifth century. Drawing on a translational approach (based on the categories proposed by the Marpa Term group), the author compares the versions of Kumarajiva, Xuanzang, Dharmacandra, Prajña and Liyan, Dharmasiddhi, Prajñacakra, and Danapala, all of which belong to the so-called Chinese Buddhist canon and aims to identify the methodological and technical translation choices of the translators. The author concludes that the early periods of translation of Buddhist texts in China, in the third and fourth centuries, saw the adoption by the translator monks of methodological choices consisting of the assimilation of Taoist terms in Buddhist texts. The author further wonders whether the translation rendered by Xuanzang in the seventh century (considered to be the best one) contains an overuse of loans. Finally, the author points out that the Chinese language allows another possibility, consisting of the combination of two Sanskrit-Chinese lexical elements, according to which the Sanskrit element belongs to the phonetic translation, and it is thus a combination of the Sanskrit phonetic translation with a Chinese character that creates a new Chinese term.

Ayadi (2009–2010) carries out a qualitative and quantitative study aiming to identify the reason why learners of English are unable to find the appropriate equivalents of English phrasal verbs in Arabic. The author concludes that, according to the findings of the study, the students' inability to translate English phrasal verbs into their most appropriate Arabic equivalents is based on their total ignorance of, and insufficient exposure to, phrasal verbs, while at the same time students tend to depend on the context – which does not always prove useful – and to translate literally. This renders the translation of phrasal verbs unacceptable.

2.2 Syntactic and Semantic Issues

Li (2010) addresses the problems and challenges existing in current United Nations English-Chinese document translation practice. The paper presents a detailed analysis of examples taken from the official UN document system and investigates the major grammatical and lexical problems influencing the readability of UN translations and the translation strategies adopted by UN translators. The author concludes by identifying three major problems: readability (stating that poor readability is due to translators' failure to choose the appropriate translation strategies), incomplete sentence structure (which mainly originates in the lack of a subject, which in turn is caused by passive voice or the lack of a subject in the original text), and accuracy of individual words/phrases (stating that mistranslations are unavoidable). However, translators are responsible for minimizing mistakes and ensuring that translations are accurate).

Miličević (2011) relates translation studies to the theory of language acquisition, by examining recent findings on some grammatical properties of translated texts on the one hand and the findings of acquisitional studies dealing with such properties on the other. As well as reviewing research into the well-known phenomenon of pronoun overuse, the author focuses on a less explored problem: the overuse of possessive adjectives, for which the author considers preliminary data from English to Serbian translations. Relying on a comparison with the results obtained in acquisitional studies of possessive adjectives, the author argues that the different cases of patterning between translation and language acquisition – in particular second language acquisition and first language attrition – show a similarity in the linguistic systems of translators and language acquirers and speak in favor of closer collaboration between both fields.

2.3 Ethical Issues

Mansourabadi and Karimnia (2013) reviewed the ideological differences between Hoseini's novel *A Thousand Splendid Suns* and its two Persian translations, by Ganji and Soleimani and Ghebrai. Based on Fairclough's approach – according to which ideology in discourse is encoded in the lexical, grammatical, and textual elements, and changes in them are indicative of a different ideology – the authors analyzed the lexical choices of the source book and the two translations in order to establish ideological differences between them. The results of chi-square showed that there were no ideological differences between the source text and the two translations. In addition, the authors found that the translators had chosen similar vocabularies in order to represent the ideology of the original author.

Kruger and Crots (2014) conducted a survey of 31 members of the South African Translators' Institute (SATI), in which respondents were asked about the translation strategies they were most likely to select in order to address particular ethical challenges. In addition, in order to understand the factors affecting the choice of translation strategies, the impact of the experience and age of the translators and the

text type and the type of ethical problem encountered were investigated. In a second stage, the survey sought to find out the reason why respondents chose particular strategies and their views on ethical responsibility. The findings show that there is an overwhelming preference for faithful translation and also reveal an interplay between personal and professional ethics as the motivation for such preference, with certain differences across text type and type of ethical problem.

3 Current Situation

In the globalized present, English is a central language that has become the privileged means of expression of science and technology, as well as of international political and trade relations, among others. English has given rise to the existence of different types of bilingualism. These types have in turn led to the dialectal diversification of English by virtue of its geographic expansion (related to the emergence of diverse English in the world) and contact with other languages, its internationalization and its influence on other languages – (The Englishization of the world's languages) which have thus been transformed – with the consequent emergence of different sociolects (Ferro Mealha 2012).

In the lexical field, that internationalization of English has had an impact on international organizations, where working languages tend to be reduced in favor of English or where English is considered to be a *lingua franca*, with its consequent influence as a supersubstrate. This is evidenced by the importation of concepts and terms created in the English-speaking world, the significant development of neologisms (This is the case of terms such as “Third Way,” “weapons of mass destruction,” bypass, airbag, e-mail, leasing, link, buffer, bit, and so on (Montero Fleta 2004; Muñoz Martín y Valdivieso Blanco 2007; Gutiérrez Rodilla 2014).), and so on (Muñoz Martín and Valdivieso Blanco 2007).

Therefore, within this framework of contact of languages, we can argue that translation is indeed a special case of such contact, given that the translator him or herself is subject to the interference of one of the languages in the other (source and target language) and, in addition, because translation allows for contact to be established in a different manner.

Within the context of a same language, it is well-known that not all speakers of a language use the same variety. Such linguistic variety can be verified by observing all of the levels of a given language. For example, terms and expressions such as “che” [“Hey”], “fiaca” [“feel lazy”], “hacerme una siesta” [“I’m gonna take a nap”], and so on are indicative of the Spanish spoken in Argentina. These varieties depend on extralinguistic factors such as the origin of the speaker, his or her age, sex, socioeconomic status, among others, and give rise to social linguistic variations or sociolects (which are thus defined on the basis of the social features of the speaker).

In addition to the speaker's features, the study of linguistic variation also takes into account where the speakers are (context), who the speakers are (interlocutor), and what they talk about (topic) in the conversational exchange. All of these issues define the situational linguistic variety known as *register*.

Within the framework of language variety, we as speakers recognize a variety of the language (Spanish in the case of Argentina) which is common to all speakers and such variety is taken as a model of the language considered and is known as *written standard variety* or *written normative language*. The different oral varieties of the language considered are variants of such language and speakers tend to attribute a greater prestige to one of the oral varieties to which they are exposed, generally the one that speakers identify with the most powerful social group (in cultural, political and/or economic terms) and the one which is closest to the written standard variety. This variety is known as *oral standard variety* or *oral cultured norm*.

Moreover, it is worth noting that languages often coexist with other languages (which presupposes the existence of bilingual speakers), and in such circumstances of *linguistic contact*, the varieties of the language spoken in such places have linguistic features that may be attributed to the contact with another language. These are the so-called *contact varieties*. A situation in which more than one language is spoken is known as *diglossia*, that is, a situation where two language varieties coexist within the same population or territory. In such contexts, one of the languages is more prestigious and is usually considered as a language of culture or of official use, while the other is relegated to socially inferior situations such as oral communications, folklore, and family life (An example of this is the one between the Spanish and Guarani in Paraguay. In this regard, Rubin (1974) notes that Spanish is the language that speakers choose to issues related to education, government, high culture, and religion, while Guarani is used to “matters of privacy or primary group solidarity” (pp. 121–122). The influence of Spanish in the Paraguayan Guarani led to the variety of Guarani known as “yopará,” while also observed in the Paraguayan Spanish, the influence of Guarani (Ferrero and Lasso-Von Lang 2011). Similarly, the contact of Spanish with Brazilian Portuguese originated *Portuñol*, which records differences in the spoken language in different places, such as the province of Misiones (Argentina) and northern Uruguay (Lipski 2011). Similarly, in northwestern Argentina, it is verified in the contact of Spanish and Quechua, showing different contributions from Quechua to the first one in the lexical field, in the phonetic loans, and in the pronunciation of the “s” (Nardi 1976–1977).). Along these lines, when three or more languages coexist in such context, the situation is one of *polyglossia* or *multiglossia* (Suriani 2008; Supisiche et al. 2010).

4 Translation

I agree with Muñoz Martín (2014) that translation and interpretation are skills that are specific to bilingual competence in the translation task. Mayoral Asensio (1999) argues that there is no homogeneous concept of translation and identifies the properties of communication in general, taking into account the maxims of Grice (1975) (Grice points out that in all those situations the readers of a translation have expectations as to the original text and its meaning, which the translator must in turn satisfy within the framework of his or her ethics. This satisfaction can be assessed by using what Grice presents as perspectives of analysis, that is, an analysis of an

assertion as to its truthfulness (quality), brevity (quantity), relevance (relation), and observance of set patterns (manner). Grice thus identifies the conditions of efficiency (maxims) in the communication of the linguistic variation, namely, adjusting to the context and the situation as specified in the translation instructions (Maxim of Quality and Maxim of Relation), adjusting the communicative strategy to the translation instructions (Maxim of Quality and Maxim of Relation), using only markers with which the reader is familiar (Maxim of Relation), maintaining only those distinctions that the reader can appreciate (Maxim of Quantity) not maintaining in the translated text those distinctions made in the original text that have no communicative function (Maxim of Quantity), using the minimum amount of markers that, along with other contextualization hints, allow identifying situational features and creating the desired effect (except in cases of deliberate alliteration) (Maxim of Quantity), not introducing unjustified ambiguities in the definition of situational features (Maxim of Quality), avoiding inconsistencies (in the case of cultural parameters, such inconsistencies may be caused by mixing features that are specific to each culture) (Maxim of Manner), and maintaining consistency in the type of markers used to point to a certain feature and the set of features of a text (Maxim of Manner) (pp. 171–172.) which allow explaining a variety of conversational translation situations and of different solutions.

Within this framework, it can be stated that a translator is faced with different circumstances related to lexical semantic, grammatical, syntactic, rhetorical, pragmatic, and cultural issues. Lexical semantic issues are related to terminological alternation, neologisms, contextual synonymy and antonym issues, lexical networks, semantic contiguity, and so on. Grammatical issues comprise aspects such as tenses and pronouns. Syntactic issues may arise from syntactic parallelism, passive voice, rhetorical figures of speech such as anaphora (the repetition of a word or phrase at the beginning of a verse or sentence) and hyperbaton (inversion of the natural order of speech) reaction, and so on. Rhetorical issues are related to the identification and recreation of figures of thought (comparisons, metaphors) and diction. Pragmatic issues are concerned with differences in use (e.g., the difference between “tú,” “vos” and “usted” to address a person in Spanish), idiomatic expressions, proverbs, humor, and so forth.

Finally, cultural issues concern the differences between cultural references. Coseriu (1977) examines the translation of culture in his analysis of the relationship between signification (signifier-signified relationship), designation (the relationship between sign and referent), and sense (the meaning as actualized in a text). He argues that the transposition of the three is not always possible when translating and that the translator must privilege designation and sense in the translation (Gentile 2012).

5 Linguistic Treatment

As far as linguistic treatment is concerned, it is worth pointing out that the norm constitutes the foundation that gives both cohesion and continuity to a language, which can thus maintain its usefulness. The norm can be understood in two different

ways: from a prescriptive perspective, with reference to an imperative of the use/correctness that tends to be unique and does not admit variations; and from a descriptive perspective, according to which the norm is what is normal, a set of characterizing features that distinguish a given language, what the majority of speakers habitually use. Thus, while speakers can deviate from the norm, such deviation is not without limits, which are given by the need to understand the message.

The speaker can – and usually does – resort to authority as a supplement to, or substitute for, the norm. In this respect, we can distinguish between (a) power-based authority, that which has a prescriptive function in the field of language, assigned in a formal manner, or which is vested with an institutional power of another type but that has an impact on the field of language (language academies, public powers, and so on and b) credit-based authority, that which the speaker trusts because he or she assigns to it a certain measure of credit (dictionaries of language use, specialists, the internet) (Muñoz Martín and Valdivieso Blanco 2007).

As an example of the above, the commentators of Sanskrit texts during the Vedic period enjoyed an authority and preeminence that could be as important as that of the author to whom the text was attributed. When commenting the texts, those commentators identified different meanings of specific terms, provided examples, cited other texts, and so forth (see Levman 2014).

6 Addressing the Task of Translation

The task of translation can be addressed in different ways, and it depends on the stance to be adopted by the translator him or herself. Chesterman (1995, 1997, cited in Schjoldager et al. 2008) describes the evolution of translation theory by distinguishing eight interrelated stages, to each of which he assigns a metaphor to describe the prevailing view of translation in each of the stages. Chesterman points out that there is a general trend to alternate between a stage of source-text dominance and another of target-text dominance in the process of translation. The stages are presented below.

Stage 1 begins in 1000 BC, and the metaphor assigned to it by the author is “translating is rebuilding.” A set of “units,” namely, words in one language, are taken and rebuilt in another set of “units,” that is, words in another language (Schjoldager et al. 2008).

Stage 2 starts in the fourth century, and the metaphor assigned to it by the author is “translating is copying.” In this stage, translators were faced with the dilemma of how to translate without changing meaning. St. Jerome, a translator from this period, presented a three-term taxonomy that has had an influence over translation studies since then: (1) faithful word-for-word translation, (2) faithful sense-for-sense translation, and (3) unfaithful free translation.

Stage 3 begins in the fourteenth century, and the metaphor assigned to it is “translating is imitating.” In this stage, many translators, instead of making a

copy-like translation, sought to imitate the creative process of the original author, thus taking a freer approach (with respect to the original text) to translation.

Stage 4 begins in the nineteenth century, and the metaphor assigned to it by the author is “translating is creating.” In this stage, some translators started to experiment with a translation style that deliberately created a foreignness in the target texts, thus giving rise to an overview of equivalence-based work in translation studies (Schjoldager et al. 2008).

Stage 5 starts in the twentieth century, and the metaphor assigned to it is “translating is recoding.” In this stage, there was considerable experimentation with the so-called machine translation. Of particular note in this period is the Prague school, which was formed by a circle of linguists that emphasized the analysis of language as a system of functionally related units. Eugene Nida, a renowned linguist and Bible translator – whose most significant contribution is the principle of dynamic (or functional) equivalence over the principle of formal equivalence (or correspondence) – is the most outstanding scholar from this period. Another significant contribution to the linguistics-oriented approach is that of J. C. Catford, his most influential contribution probably being the notion of shifts.

Stage 6 begins in the 1970s, and the metaphor assigned to it is “translating is communicating.” In this stage, translation studies became a separate discipline. Some developments in general linguistics seem to have paved the way for the independence of translation studies as an academic discipline. Language studies no longer revolved around the phrase, and the context acquired more importance (Snell-Hornby 2006). Translation studies were greatly influenced by text linguistics and pragmatics, among which Grice’s theory of conversational implicature and the contributions of de Beaugrande and Dressler and, more recently, of Hatim and Mason have been highly influential. Many scholars from this period rejected the notion of equivalence and replaced it with target-text functionality as the controlling factor in translation processes. Such studies were developed by German scholars, with the *Skopos* theory by Hans J. Vermeer being the most influential (Schjoldager et al. 2008). This new approach gives more visibility to the translator, who, according to Christiane Nord, remains solely responsible for the loyalty of the translation (Vidal Claramonte 1995). While loyalty can be understood from different points of view, this new approach to translation is particularly relevant in the field of intercultural translation, given that the translator is in the privileged position of deciding how to translate what he or she translates, thus conveying one message or another in the target culture.

Stage 7 also begins in the 1970s, and the metaphor assigned to it is “translating is manipulating.” During this period, concurrently with the developments in Stage 6, a group of Israeli and Belgian scholars developed a new approach to translation studies. This was a break with the trend toward prescriptivism followed by scholars from previous stages. These scholars followed Holmes’ (1972) proposal for emphasis on descriptive translation studies. A particularly influential scholar in this stage was Gideon Toury, who focused on the translator as a social agent.

Stage 8 begins in the 1980s, and the metaphor assigned to it by Chesterman is “translating is thinking.” This stage ushered in a growing interest in the translation

process and the use by scholars of cultural studies tools for the study of translation from a cultural, sociological, and cultural perspective (Schjoldager et al. 2008).

The idea that “translating is not neutral” became increasingly prominent. Along these lines, Robinson (1997) points out that translation has always served as a mechanism of conquest and occupation. That is, during the colonization process a network of hierarchical relations is created through discourse that eventually consolidates and spreads across time and space. In addition, the concept of otherness gains impetus within the theory of postcolonial translation, due to its presence in the works of authors that live in contact with two different civilizations and cultures, who look for specific forms of expression that give voice to both languages and cultures, with consequent social and political implications. Not only are the messages conveyed important but also the manner in which they are conveyed, making it necessary to review the role of translation in the representation of other cultures (Sales Salvador 2004) (Dovidio et al. (2010) sustain that stereotypes are cognitive schema used by social percipients to process information about others, reflecting not only beliefs regarding the characteristic features of group members but also information about the diverse qualities of those “others,” influencing the emotional reactions toward the members of that group. Associated to this, Pedulla (2012) points out that stereotypes may play an important role in molding attitudes, often being related to discrimination and prejudice.).

Translation studies have currently evolved in so many directions that it is difficult to determine which of them is more typical (Schjoldager et al. 2008). Within this framework, the colleagues whom we interviewed refer to their own positions and translation logics. An Indian colleague, aged 45, who translates literary texts – moving in a universe of English, Hindi, and Spanish – states that: [...] “I need to acquire the sense of the text. I always want to drown in the original.” An Argentine colleague, aged 65, who also translates literary texts (essays, theory and poetry) from French, English, and exceptionally Japanese (classical poetry) into Spanish suggests that she usually reads the text in the original language first, checking if there are terms that may give rise to ambiguities and solving that using appropriate sources. After that, she begins to translate, taking into consideration not only the correct syntax but also the appropriate rhythm. Another Argentine colleague, aged 50, who does interlinguistic translation work of literary, philosophical, religious, and legal texts elaborates that as a university professor and scientific researcher, she uses translation not as an end in itself but as a didactic tool. She uses the method of grammar and translation, meaningful learning, and contrastive linguistics.

7 Difficulties, Strategies, and Rules in Translation

In analyzing the possible strategies to be adopted when translating, Venuti (1995) sets a series of parameters that mark and define the translation process. He provides a classification based on the degree of alienation of a translation, its fluidity, and the type of existing relationships between cultures. He makes reference to what he considers a good or bad translation in those terms, considering thus that while a

fluid translation is that where the language used combines the literary standards of the target language with the “marginal” aspects of the source in such a way that cultural and linguistic differences show, a bad translation shapes an ethnocentric domestic attitude revolving around the foreign culture.

Different areas of study offer diverse terminological features, and the manner in which they are approached varies from one translator to another. The Indian colleague notes that:

The most common difficulties are not grammatical (...) and I think that nothing is untranslatable. It all comes down to finding the appropriate equivalent. So I look for such an equivalent in the social experiences of the culture of the target language, in its myths and legends and in its society... I think that we are all human and that all societies have the same experiences. Then, all of us have the necessary vocabulary to convey those experiences and it is just a matter of knowing where to look and go for it.

On some occasions, for example, when translating a “Chick-lit” novel from English into Hindi, I was having some lexical issues... (as) I don’t believe I have the necessary vocabulary in Hindi to express feelings/intimate experiences (taking into account her own Hindi background and leaving the possibility open for more considerations from and about translators from the same perspective).

On the other hand, one of my Argentine colleagues comments that:

The difficulties of English and French texts usually lie in idiomatic expressions, in not over-expanding where the language is concise, that is, problems related to the lexical and syntactic fields. In the case of Japanese, from which I’ve translated some poetry, we encounter more problems as there are no morphological coincidences: elements like number are not necessarily marked in Japanese, which also has a smaller variety of tenses and, as a result, there arises a need to choose from the different possibilities in Spanish. Besides, as this is a culture that carries a strong stamp concerning objects, habits, clothing, etc., I consider that the term should be kept in the source language and notes or comments should be included.

Similar resources are used by prestigious indologists Tola and Dragonetti (1999; Dragonetti and Tola 2004), who make use of introductions which put translated texts in context and describe the development of their study, including notes and sections with key concepts in order to clarify terms and concepts under analysis and to facilitate the access to the semantic network that sheds a light on the text and the subject itself. Another Argentine colleague suggests that:

One of the most common difficulties when translating from a very rich and concise language is finding equivalents in other languages that lack those characteristics. For example, a complex structure, including subordinate clauses, is needed in Spanish in order to translate an idea that in Sanskrit is conveyed by a nominal phrase.

In the lexical field, a highly interesting example is that of the multidisciplinary group Marpa Term of the Departament de Traducció I d’Interpretació de la Universitat Autònoma de Barcelona, which studies Tibetan Buddhism in the West from a translation-related perspective and in this context develops a terminological database. The group points out the coexistence of diverse areas of study of

Buddhism that fostered different translation methods, which in turn result in the coexistence of different equivalent terms seeking to translate the same term in the source language. The source of its database is Tibetan, and the target languages are Spanish and Catalan. The group carries out a prescriptive task that aims to generate proposals to normalize the use of terminology in Spanish and Catalan in the context of Tibetan Buddhism. Each entry includes the Tibetan term in its original form, in the Tibetan alphabet, and its Wylie transliteration, together with its equivalent in Spanish and Catalan (also including its equivalent in English, French, and Sanskrit). It also includes a section which refers to the translation technique applied so that the user may understand how the proposed equivalent was achieved. With respect to the translation techniques considered, an order of priority is proposed as follows: equivalent, context equivalent, coinage, periphrastic translation, calque, and loan (Martínez-Melis and Orozco 2008).

In addition to any lexical issues and their equivalents, the creation of neologisms, syntactic adaptations, and the solution to agreement difficulties, there are space-time considerations involved in the text constructs under analysis. In this respect, it is worth noting that a translation, both as an activity and as a product, falls within a specific social context, determined by specific linguistic, political, cultural, and socioeconomic coordinates, which at the same time renders a text that also accounts for such coordinates. The sensitivity of this issue is related to the fact that time and space are founding variables of social relationships, paramount both for the creation of the text as well as its reception and understanding. This raises the question of how effectively establish a co-participation in space times considered by translating and if that practice contributes to a kind of intellectual genealogy of the own translator, in the deep heuristic sense of the question (Personally, I consider that the way such issues are addressed has scope to rescue the interpellation of the translated texts into the present affairs (with a corresponding impact on translation competence).).

Vibha Maurya (2008), in her translation of *Don Quixote*, from Spanish into modern Hindi writes:

Besides, I consider that there is something even more meaningful. As a translator, I find myself in a very different place culturally speaking and in a fairly distant historical time. Consequently, it was necessary to make a temporal and linguistic adjustment. I think that, as a “(re)writer” of a text in its translation, it is my duty to bring the readership closer to the text as well as the text closer to the readership, so that the translation is aimed at treading a double path. I am fully aware that in this process as a whole there are several losses but also a few gains for the target language. The translation of *Don Quixote* into Hindi is intended to make the literary world of our language richer, I believe.

Throughout my career as a translator of literary works, I have witnessed a process which is composed of two branches which are interdependent of the social system: the linguistic branch and the sociocultural branch. (pp. 546–547) (Her assertions are complemented by those of Maurya (2015, p. 4), where she stated that “faithfulness has nothing to do with literality; this practice not only ruins a translation but also distorts the relationship between the translator and the original author (. . .) The language of the author is not, after all, just a bundle of words or a fortuitous lexical collection, a random syntax. Each word, each lexical item, is carefully selected, its direct meanings and its connotations are so complex that they seem to be constantly rebelling. In fact, the rendering process is like a vortex of meanings — where a translator sinks and spins in order to obtain equivalents for words in both languages

(...) That is why faithfulness may be a sincere ideal goal of the translator of literary works but it is completely utopian (...).”

In considering an intercultural context, translators, who find themselves between two cultures, must know them both, their rules and differences, in order to be able to apply the necessary strategies in an appropriate manner, thus obtaining different results in each case (Toury 1995). Venuti (1995) argues that the translator must break certain rules shared by the members of the target culture to guarantee the rendering of the message and the source identity, but he or she must also comply with some of those rules to prevent the translation from being rejected, thereby finding the middle ground. The greater the level of acceptance of a text in the target culture, the more changes made to the target text with respect to the source. This will result in the text being closer to the readership and will make the translator invisible (as a discourse effect that depends on how the translator handles the translation and how the public reads and assesses it).

Nord (1989, 1997) meanwhile proposes a model to develop the translation process from a functional approach called “the looping model.” It considers the translation process as a circle rather than as a line and makes reference to the responsibility translators have toward their partners, referred to as “loyalty,” a principle first introduced by the *Skopos* (Translation theory proposed by the German translator Vermeer in 1978, who claims that the principle that defines the translation process is the *Skopos* (purpose) of the transactional action (Jabir 2006).) theory, which tries to account for the cultural features of translation concepts by setting an ethical limit to the range of possible *skopoi* for the translation of a specific source text (Nord 2006).

Hatim and Mason (1995), who start with the elements that comprise the text structure, analyze the relationship between discourse processes, and translation practice, taking into account the motivations of both the author and the translator. They analyze language as text within a cultural and situational context, giving importance to the pragmatic, semiotic, and communicative values of discourse, the context elements whereby the translator captures the intention of texts. House (1997), on the other hand, a predecessor of Hatim and Mason, may be classified within the functionalist translation theories because of her sociocultural perception and her influence in functionality concepts, both of the source text and the translation.

8 Translation Competence

In line with the above statements, besides the bicultural perspective presented by Hatim and Mason (1995), several authors acknowledge the development of a translation competence. For example, Muñoz Martín (2014) proposes a construct for translation expertise consisting of five dimensions: (1) knowledge, (2) adaptive psychophysiological traits, (3) problem-solving skills, (4) regulatory skills, and (5) the self-concept. These dimensions are regarded as scopes in a complex behavior,

and they do not imply any “internal” separate mental activity (p. 17). On the other hand, in 1997, the PACTE (Process Acquisition of Translation Competence and Evaluation) group was created. The group was formed in order to analyze the acquisition of translation competence (ATC) in written translation, and in 1998, they developed a holistic model which established several basic premises.

In this regard, the group conceives translation competence as the underlying system of knowledge necessary to translate; it is, therefore, regarded as expert knowledge comprising both procedural and declarative knowledge. It is by virtue of this competence that the translator is able to perform the translation process. They also consider that translation competence comprises several sub-competences (language, extralinguistic, knowledge about translation, instrumental, psychophysiological and strategic) as well as psychophysiological components.

Considering the different sub-competences, we can say that the language sub-competence refers to the expert’s ability to switch between both languages, and it comprises pragmatic, sociolinguistic, textual, grammatical, and lexical knowledge (PACTE Group 2003). The extralinguistic sub-competence consists of “[...] declarative knowledge, both implicit and explicit, about the world in general and special areas” (PACTE Group 2003, p. 58), whereas the “knowledge about translation” sub-competence implies that the translator needs to know how translation functions: “types of translation units, processes required, methods and procedures used (strategies and techniques), and types of problems, as well as knowledge related to professional translation practice: knowledge of the work market [...],” and so on (PACTE Group 2003, p. 59). The instrumental sub-competence refers to knowledge related to the use of documentation sources and information and communication technologies applied to translation – the use of dictionaries, encyclopedias, glossaries, and so on (PACTE Group 2003).

These sub-competences are complemented by certain psychophysiological components: (1) cognitive components such as memory, perception, attention, and emotion; (2) attitudinal aspects such as intellectual curiosity, perseverance, rigor, critical spirit, knowledge of and confidence in, one’s own abilities, the ability to measure one’s own abilities, and motivation; (3) abilities such as creativity, logical reasoning, analysis and synthesis, and so on (PACTE Group 2003, p. 59). When translation is performed, these sub-competences interrelate establishing a hierarchy that depends on the specific work, and different variants are possible depending on different factors (text, context, translation experience, and so forth). Here, the strategic sub-competence plays an essential role in that it regulates and compensates all the other sub-competences.

9 Implicit Ethical Issues

Inghilleri (2009, p. 102, cited in House 2016, p. 27) states that “once the space between the translator and the text (...) is acknowledged as irrefutably ethical, the task of the translator cannot be viewed as simply linguistic transfer, while this is understood as segregated from an ethical injunction.” The idea that translation, the

social context, and the translator's position/stance are closely related is not new but has been emphasized in recent years. In this respect, House (2016) considers that this new emphasis lies in conceiving culture as a space of ideological struggle and the translator as a "stimulator" resisting the influence of hegemonic structures. In line with this approach, translation may also be considered ideology. Along the same lines, there has been significant production regarding the "politics of translation" and the perception of translation as a space for political action (Baker 2013), these considerations arising within the framework of the relation between translation and conflict scenarios.

Ethical issues in translation, therefore, seem to be related to a large and complex tension between the literal rendering of the source text and a translation that considers the expectations of the target language's readership taking into account the cultural context and the text's function in the target culture. Alwazna (2014) proposes a middle ground between these approaches, paying special attention to the nature of the text, the purpose of the translation, and the readership. İçöz (2012), in turn, aims to identify those situations in which a translation becomes unethical. The author refers to a prejudiced version, misinformation affecting the translation on purpose or by mistake, among others. In any case, it is clear that translating requires the translator to perform a constant critical and reflective analysis over his or her work and over him or herself.

The colleagues whom I interviewed explain their positions with respect to this tension that raise, is resolved, and rise again. In an Indian colleague's view, "a translator should make sure the translation is an echo of the original without losing sight of the target language's reader." An Argentine colleague adds that:

I try to be faithful to the original; I'm not keen on recreating, adapting or looking for rhymes when the original text makes use of them. I always try to make the resulting text nice to the ear and make it adapt to syntactic rules in Spanish. I have never ventured into the translation of texts which are avant-garde or experimental in the source language.

Another Argentine colleague also remarks that:

It is essential to be as faithful as possible to the original, producing a text equivalent to the original and, for this purpose, subjective considerations should interfere as little as possible in the end result of the translation process. Translation should not be used as an ideological weapon.

Regarding the unavoidable reflection about the power that operates in translation, the respondents allude to the relationship of language with spatial semiotics, which opens another dimension to deepen: the relationship between language, space, and power (It seems relevant to remember Tally, when he says that "*To draw a map is to tell a story*" (Daricci 2015)). Thus, for an Indian colleague:

I find great pleasure in translating from Spanish into Hindi and from Hindi into Spanish. In my opinion, translating directly from Spanish into Hindi works in two ways. Hispanic literature in India is mostly known through translations from the U.S. and Indian literature – I'm referring only to literature in Hindi – is not known in the foreign world, except for religious texts. This is why it is so important for me as a translator to work with these two languages.

An Argentine colleague also remarks that:

Language is a defining and essential aspect of all peoples and nations. History shows the unavoidable association between power and language: for example Latin's role in the invasion and dominance of the Roman Empire, or Spanish in the discovery and colonization of the Americas. In this age, rather than through weapons and war, power is imposed through other levels: technology, commerce, and science, and in this sense, it becomes difficult to find answers or solutions. Spoken language, if not recorded, will be lost – there always were and still are many communities that don't use a written language. In my opinion, in large societies, the power of the dominant language pervades fields like commerce and science; whereas in the minority languages the arts (literature, songs) are preserved.

Within the framework of this analysis, I think it is essential to address the subject of the written word: This applies to China, which despite its industrial and commercial power, uses a complex (spoken and written) language that is very much restricted and is usually replaced by English for the signature of treaties, conventions, etc. (Rodriguez (2014), links the promotion of language to the notions of "soft power" and "nation branding" and points out the successful cases of the United States and China in this task.)

Another Argentine colleague adds that:

I think the translator's task as an agent that promotes cultural visibility is extremely important. This transference should be serious, scientifically founded and devoid of superimpositions germane to the culture of the target language. It is also very valuable that there are now more "languages of knowledge.

The experiences of my colleagues bring to the fore important aspects of the translation process, such as the projection of a concrete identity through translation and the resulting active and conscious participation in an intercultural dialogue process, the "reading" of language use and its geopolitical implications, and the space of empowerment of some languages in relation to others, as knowledge seems to be associated with certain specific languages (while others could appear as "repetition" of the former) (Ferro Mealha (2012) addresses the use of English as the language of academic and scientific discourse and points out the bias to which it can lead to not knowing the language and not publishing in English.). All of these matters – which require a thorough and focused analysis – relate to the observations made by Restrepo (2010) in the sense that identities (thinking about the identity of the author, those identities which the text realizes, the one of the translator, the ones of the readers, and so on) are not only concerned with differences but also with inequalities and domination; that is to say, identity demarcation practices are connected with the preservation or confrontation of different hierarchies (at the social, political, and other levels).

10 Conclusion and Future Directions

The all-important role that the translator has had throughout history as a mediator between languages/cultures acquires special significance today, in a context of enormous technological advances that on the one hand seem to facilitate the translator's work but on the other may also condition it.

Contact between cultures evidence the dynamics of power at play in those relations, which has an inevitable influence on the translator, the translation process, and the end product. In other words, “translating is not neutral” (and translators are not mere “technicians”). Therefore, since the translator decides what to convey and how to convey it, his or her stance becomes essential in the translation process and, consequently, in the representation of the others and the process of the cross-cultural research of which it is part. Furthermore, and in accord with the notion that the translator is influenced by an epistemic subjectivity (as he or she requires previous knowledge in order to translate, but he or she also knows the task of translation itself), I agree with Retamozo (2007, quoted in de la Vega Rodriguez 2015), who considers that the construction of such subjectivity is the result of a position that articulates volition and consciousness in an indivisible manner with the translator’s ethical and political stance.

Thus, while an Argentine colleague notes that she cannot conceive intellectual work and research in any field without the aid and use of translations, my Indian colleague states that:

In answer to the question of “what is translation?”, Umberto Eco states that it is “saying almost the same thing”. The key lies in that “almost”, which makes us understand that translating can never imply an exact literal transposition of the meaning of one text into another, written in another language. On the contrary, it involves a process of cultural negotiation.

She also contends that:

Translation is a bridge between two languages and cultures. It is important that the bridge we build is nice and strong, and translators play a very important role in this. The significance of this cultural change is undeniable, even in today’s globalized world.

Regarding the above statement, an Argentine colleague adds: “I respect and adhere to the Buddhist principle that we should ‘reach each person in the language he or she speaks’. In this sense, the translator is a true pontiff, in the etymological sense of the word, i.e. a ‘bridge-builder.’”

I thus perceive a translator as a kind of bridge builder, an agent and manager of linguistic change, who recovers cultural agency and empowerment through translation, in the understanding that the link between knowing a language and applying that knowledge is not an innocent one. On the contrary, the construction of meanings around the subjects, their relationships, and their productions carries sociopolitical consequences, thus destroying, reconfiguring, and/or constructing new frontiers. In this context, the translation strategies do not appear as a certain and fixed itinerary but rather as a compass that guides the translation, while representations of otherness are always relational and relationships, although similar, are always unique.

Being an integral component of cross-cultural research, translation raises ethical, epistemological, and practical questions inherent in a research. Considering the possibility of imposing another conceptual framework on the translated subjects

(and their correspondent cultural contexts, values, life worlds, languages, texts, and so on), it is evident that the need of reflexive approach to translation not only to overcome difficulties involved in cross-cultural research but also to take a stand on the implicit element of power in the situation (that concerning hegemonic and non-hegemonic cultures/languages). As translators, researchers, and/or researchers/translators, we have personal sociopolitical positions that impact not only in the product of research but also the interpersonal relations in the fieldwork. In that sense, our multilingual identities influence and impact our “locations.” Researchers (and)/translators should then recognize the linguistic and cultural differences that data translation must negotiate, preserving and highlighting cultural differences rather than resembling the dominant values of the target culture by translation. Thus, the acknowledgement of the translator’s roles as intercultural communicator and data interpreter in the research process shows the importance of the translator as an integral part of the knowledge production system (see also **Finding meanings: A cross-language mixed-methods research strategy and Conducting cross-language qualitative research with people from multiple language group**).

All these elements are important to consider the rigor of the research and that emphasizes the need to understand and recognize the critical importance of language in the generation of knowledge and its cultural interpretation. For that reason, the debate and constant reflection on translation/interpretation in cross-cultural research should involve “the hierarchies of languages, power, the situated epistemologies of the researcher, and issues around naming and speaking for people who may be seen as other” [. . .]. “speaking for others, in any language is a political issue, which involves the use of language to construct self and other” [. . .] “translating itself has power to reinforce or to subvert longstanding cross-cultural relationships but that power tend to rest in how translation is executed and integrated into research design and not just in the act of translation per se” (Temple and Young 2004, cited by Alzbouebi 2010, p. 7). Translation (and the given interpretation) is about understanding that language is connected to “local toponymies” (space, historical time, identity, culture, the social apprehension of reality and its narrative, and so so); all of which are crucial for any cross-cultural research.

It is then necessary to discern how we can be more faithful to the sources we translate (subjects, cultures, identities, texts) and assume that all this involves operations with different temporalities (that of the moment of translation and that related to the history of what or whom we translate and the one related to who does the translation), spaces (the one of the translator, that of what or who is translated and the space for which the translation is done), and the memories related to all that (the implicit and explicit memories in what is translated, who translates, and the memory of the translator, that activate the life trajectories involved). As Richard points out (2002), the name implies a cut and modeling of a category of intelligibility, and, as we have said, this is not dissociated from power as an element of social relations, of which we finally go to give account in the cross-cultural research processes we develop.

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Finding Meaning: A Cross-Language Mixed-Methods Research Strategy

94

Catrina A. MacKenzie

Contents

1	Introduction	1640
2	Finding Capable Interpreters	1641
3	Interpreter Social Position and Subjectivity	1643
4	Survey Translation Challenges	1646
5	Self-Reported Disease Load and Implications for Conservation Research	1647
6	Conclusion and Future Directions	1648
	References	1650

Abstract

The literature devoted to methodological issues arising from working through an interpreter is surprisingly sparse. References that exist tend to be dated anthropological works or tend to focus on interviews in social work and medicine. The older literature tends to focus on the mechanics of translation and how to conduct an interview with an interpreter, while more recent works start to address the issues of whether the interpreter should be “invisible” or whether the changing dynamics of the interview with an interpreter present merits the rigorous treatment of the role and influence of the interpreter with respect to power and subjectivity. Interpreters are fundamental to the research process when a foreign researcher is conducting research with an indigenous culture, and when the researcher is not fluent in the local language. In this chapter, an experientially developed cross-language research strategy is discussed, including choosing and assessing the linguistic skill of interpreters, the influence of interpreter social position and subjectivity on transcript data, and the challenges encountered when

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1639

translating and conducting a household survey, including questions about self-reported illness. The chapter ends with a summary of the components needed for a successful cross-language strategy, including the need to acknowledge the limitations introduced as a result of working through an interpreter, and the need to make the role, credentials, social position, and subjectivity of the interpreter explicit in published results.

Keywords

Language interpretation · Translation · Social position · Subjectivity · Cross-language research

1 Introduction

Using qualitative, quantitative, and Geographic Information Science methodologies, my research aims to understand the spatial distribution of perceived and realized benefits and losses accrued by communities as a result of the creation of protected areas. My research is positioned within the local socioeconomic context of the protected area and investigates how incentives, disincentives, and household well-being influence conservation attitudes and behaviors of local people around Kibale National Park in Uganda (MacKenzie 2012; MacKenzie and Hartter 2013). Working in 25 villages located around the park, I and my team of Ugandan research assistants first collected general perceptions about the benefits and losses associated with living near the park during focus groups, and then conducted a household survey to collect more detailed information about perceptions and attitudes about the park and specific data to assess household well-being. Household well-being can be assessed in many ways: reported income (Montgomery et al. 2000), objective capital assets (Takasaki et al. 2000), access to education, medical care and clean water (Vyas and Kumaranayake 2006), self-reported health status (Michalos et al. 2005), or subjective happiness (Bookwalter et al. 2006). Since the residents around Kibale National Park are primarily smallholder farmers with no permanent income stream, I elected to assess well-being based on the ownership of capital assets, educational attainment, access to sanitation and clean water sources, and self-reported diseases suffered by household members in the prior 5 years.

Uganda recognizes 32 distinct languages (Mukama 2009). In school, children are taught English and Kiswahili, but only 24% of the adults in my household survey sample (596 households) had completed primary school and, therefore, only spoke local tribal languages. Around the northern border of the park, a majority of households affiliated with the Batoro tribe and spoke Ratoro, while around the southern borders people affiliated with the Bakiga tribe and spoke Rakiga (Hartter et al. 2015). Since native Ratoro and Rakiga speakers are rare outside of western Uganda, I did not have the opportunity to learn these languages prior to starting my field research. I, therefore, had to incorporate language translation into my research design. Searching the literature at the time (2008), I found few papers on the effects that language interpretation could have on qualitative and quantitative data

collection, especially how the social position and subjectivity of interpreters could influence the discourses I sought to study (although see Temple 2002; Temple and Edwards 2002; Temple and Young 2004). In this chapter, I discuss my experiences creating a cross-language strategy for my research, including how I chose the interpreters for my project, learning about the influence of interpreter social position and subjectivity on focus group transcripts, and the challenges encountered when translating and conducting the household survey questions for self-reported illness.

Interpreters are fundamental to the research process when conducting research in a location where the researcher is not fluent in the local language (Liamputtong 2010; see ► Chap. 95, “An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups”). Interpretation involves, not only finding meaning based on vocabulary and grammar but also infusing that meaning with the local context and culture of the study location (Esposito 2001). Our interpreters often do much more than just translate words. They can also act as cultural brokers, modify translated meaning to protect certain interests, provide insight into local customs, and use their position as assistants to a foreign researcher to gain status within the local community (Schumaker 2001; Liamputtong 2010; Chilisa 2012; Caretta 2015); leading some researchers to describe interpreters as “gatekeepers of meaning” (Heller et al. 2011, p. 75). Methods to improve interpretational accuracy will be discussed in this chapter; however, the influence of differences in social position, gender, age, and education between the participant, interpreter, and researcher will still influence what is communicated, translated, and understood (Temple 2002).

2 Finding Capable Interpreters

Upon my arrival in Uganda, fellow researchers and staff at the Makerere University Biological Field Station were quick to suggest potential research assistants for my project. However, most of the people working as research assistants in and around Kibale National Park did so in support of forest ecology and biology projects. Few research assistants had experience in social research methods and those who did were fully employed with long-term land-use and zoonotic disease transmission research programs. It is recommended that interpreters who have achieved proficiency and accreditation in their language skills be employed for research purposes (Kapborg and Bertero 2002; Squires 2009). However, accredited interpreters were not readily available at my remote study location. Therefore, I initially hired three potential research assistants who had been recommended to me: Peter, Mark, and Brian (Mark and Brian are pseudonyms, but Peter requested his real name be used).

There are numerous means of adding rigor to the interpretation process in cross-language research. For my research, I included triangulating between interpreters and data collection methods (Esposito 2001; Temple and Edwards 2002), and ensuring my research assistants were familiar with the technical terms to be translated and the research aims prior to interviewing participants (Irvine et al. 2007). In addition, my research assistants and I discussed interpretation challenges throughout data collection

(Larkin et al. 2007) and used forward-backward translation of the focus group question guide and the household survey (Werner and Campbell 1973; Liangputtong 2010). Forward-backward translation, where one interpreter translates the questionnaire into the local language and then another interpreter translates it back into English, highlights translation discrepancies and inappropriate use of terms, identifies ambiguous interpretations, and can be used as a means of familiarizing the interpreters with the aims and tone of the research (Edwards 1998). Forward-backward translation also gave me the means to assess the language proficiency of my research assistants.

Residents local to Kibale National Park do illegally extract resources from the park (MacKenzie et al. 2012) and often perceive the park as a source of problems rather than benefits (MacKenzie 2012). These same residents also experience many diseases but are located far from medical care which is why McGill University students and researchers working in Kibale National Park raised money to start a small medical clinic near Makerere University Biological Field Station to try and help local residents and improve community perceptions of the park (Chapman et al. 2015). As part of the medical clinic start-up, a community needs assessment survey was conducted. I offered to pay my three assistants to translate the survey into Rutoro and Rakiga, then the clinic nurse back-translated the survey into English. Performing the forward-backward translation process found that Peter and Mark were very good translators, but that Brian was not. Therefore, Peter and Mark continued employment with me as my research assistants for the remainder of that first field season and in many future field seasons.

The mechanics of the interview change when working through an interpreter. The interview will take at least twice as long to allow time for language translation (Freed 1988). Since the translator and research participant are the ones directly speaking to one another, eye contact between the researcher and the participant becomes difficult, and therefore, creating a triangular seating arrangement is recommended to try and retain the researcher/participant connection (Phelan and Parkman 1995; Edwards 1998).

It is also important to conform to local social etiquette and a locally hired interpreter can be especially helpful, guiding the researcher about acceptable decorum in a given situation (Freed 1988). For example, when my research project started, local people were apprehensive of allowing their voices to be recorded, so Peter and Mark advised me that I should not use a recording device and that the focus group participants requested no pictures be taken. Since the interviews and focus groups could not be recorded, transcripts had to be written quickly while interacting with the research participants. Employing two interpreters minimized losing valuable participant comments. Peter was the lead interpreter during individual interviews and facilitated the focus groups. Mark also attended all interviews and focus groups. Peter would ask questions in the local languages, verbally interpreted what people said, and I wrote down Peter's interpretations. This allowed me to redirect questions, something I could not have done if the interviews had been recorded and then post-interview interpretations had been performed. Mark directly wrote down in English everything he heard the participants say in the local languages. Pooling both

sets of transcripts I gained a more nuanced understanding of the discussion that had taken place, captured more participant comments, and highlighted some differences in interpretation between Peter and Mark. After interviews we would discuss the transcript notes and any differences in interpretation of what had been said. This process led to a reasonably rigorous means of capturing the meaning of what the participants had said. However, 10% of the comments interpreted by Peter and Mark during focus groups did convey different meaning and/or emotional context.

3 Interpreter Social Position and Subjectivity

As researchers, our own social position and subjectivity can influence our research because our status, gender, age, and ethnicity influence how and what our participants choose to reveal to us, and because we interpret qualitative data through the lens of our own world view (England 1994; Kobayashi 1994; Dowling 2005; see ► Chaps. 91, “Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women,” and ► 92, “Researcher Positionality in Cross-Cultural and Sensitive Research”). Reflexivity, defined as “self-critical sympathetic introspection and the self-conscious analytical scrutiny of self as researcher” (England 1994, p. 82), can help us be aware of the differences between researcher and participant, allowing us to look for potential bias and adding rigor to our qualitative research (Baxter and Eyles 1997; Rose 1997; Valentine 2002). I knew my social position could influence knowledge production; as a white academic, I was seen as a person who might be able to help with school fees or could potentially direct nongovernmental organizations to aid local people, so people might present their situation to be worse than reality in the hope of enlisting my help. However, the social positions of Peter and Mark might also have influenced the participant responses or how my assistants interpreted interview responses. I not only needed to reflect on my social position but I also needed to understand the social positions of my research assistants. To do this, I developed a key informant interview as recommended by Edwards (1998) and Temple (2002), asking each assistant about their age, education, status in the local society, standard of living, power dynamics during interviews, and their perceptions about the research topic (see also ► Chap. 96, “The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research”).

Comparing the differences in focus group comment interpretation with these key informant interviews did identify themes that may have resulted in interpretational differences as a result of Peter and Mark’s social positions and research topic subjectivity. For example, Mark grew up in a village located right next to the park and had previously worked for researchers studying disease transmission between primates inside the park and zoonotic disease transmission between primates and local residents. This prior work experience coupled with Mark’s desire to become a nurse might account for the clinical terms used when interpreting focus group

comments about disease transmission; indicating Mark might have elaborated upon participants' comments.

Peter: Tsetse flies are infecting people and animals.

Mark: Vectors like mosquitoes and tsetse flies that bite people and make them sick are here.

Mark's friendship with Uganda Wildlife Authority rangers, and having both his and his brother's employment dependent upon following the park rules, may have led Mark to omit issues of Uganda Wildlife Authority ranger corruption from his interpretations. Mark emphasized the park rules and minimized the punishments for breaking the rules when interpreting participants' experiences with the rangers.

Peter: If we enter the park, we are arrested by the rangers and they squeeze money from us and take our firewood too. Even if we cut a tree, they fine us. If we go to the park for medicinal plants or if the cows go into the park, the rangers catch and squeeze some money out of us.

Mark: We are not allowed to access some resources like thatching grass, poles, hoe handles and firewood. If we do, we are always arrested. We are not allowed to pick medicinal herbs. When cows cross to the park, we are arrested.

Peter: When digging and burning the garden, if the fire goes across to the park we are arrested. The arrest involves caning. The arrest is quite bad.

Mark: When we clear and burn our plot and the fire crosses to the park, we are arrested. We have even sustained corporal punishment.

Peter's background also influenced how participant comments were interpreted. Peter admitted that he "used paraphrasing where possible to try and ensure understanding for both the researcher and respondents," prioritizing cultural interpretation over literal accuracy. Mark, on the other hand, kept his interpretations more anecdotal reflecting the way people do really speak in the area.

Peter: When things are decided top down, they don't work out. Therefore, they should start from the grass roots to ensure the right things happen. We have bitterness towards the LC5 [District], LC3 [Sub-County] and LC1 [Village] chairmen. We don't want them to get the money. The money should come straight to us so we can manage it.

Mark: Park fund management policy should start from LC1 [Village] to LC5 [District], ascending order not from LC5 [District] to LC1 [Village], descending order. The 20% that comes back is very small. It is like when you are very hungry and you come across a person with a pan full of cooked bananas, and they just give you one piece. Will you really be happy?

Peter knew I was researching the potential for local community reciprocity by improving conservation behaviors in return for park-based benefits received. Peter's interpretations tended to speak to the need to modify management processes, potentially embellishing the words of the participants to indicate intentions to reciprocate with good conservation behaviors for certain types of benefits from the park. In his subjectivity interview, Peter could not decide if he was pro-park or pro-people (a contrived dichotomy introduced into the interview to discern the potential

for bias), and if people did reciprocate for park-based benefits this would put the people living next to the park in a good light and support the provision of future benefits from the Uganda Wildlife Authority as a valid mechanism for improved conservation. Mark, on the other hand, quickly stated he was pro-park because of all the benefits his family had received due to living next to the park and a wildlife authority outpost.

Peter: We should act communally. UWA [Uganda Wildlife Authority] provide the trench and we should work together to maintain it and work together with UWA. It is our duty to protect the park, if UWA gives us the money for a trench.

Mark: We should be good stakeholders. If the park gives money for a project, let us raise our hands and support it because the park itself cannot come and provide local labour.

Being able to link differences in interpreted transcripts to my assistants' social positions and subjectivities confirmed the importance of interviewing Peter and Mark, and reinforced the need to critically reflect on how the focus group transcripts could and should be analyzed. Since only 10% of the comments were different, this gave me confidence that most of the interpretations were representative of what participants had said. However, what was I to do with the interpretations that did differ?

The words of the participants had obviously been filtered, therefore any knowledge created from those comments were situated by the interpreter's subjectivity (Caretta 2015). To deal with this dilemma, I took a multistep approach. Firstly, I tried to be particularly vigilant, reflexive, and transparent about methodology (Bailey et al. 1999), especially acknowledging the existence and role of interpreters in publications, demonstrating that I was aware of the limitations introduced by working through an interpreter in cross-language studies (Squires 2009). Secondly, the fact that I had used more than one interpreter added rigor as interpretations could be triangulated (Baxter and Eyles 1997; Esposito 2001). I also triangulated data sources using a household survey, key informant data logs, and ecological evidence of resource extraction from the national park, to cross-check the qualitative data. Thirdly, having interviewed the interpreters, I could at least partially understand how these interpretation differences altered the discourses I sought to analyze. However, as Temple (2002, p. 851) discovered when she conducted interpreter interviews, "I was not sure if the extent to which the views I was picking up were those of the two support workers [her assistants] or of the people they interviewed." Accepting that knowledge is situated and constructed by the social relationship that occurs during data collection, by our social position, and interview style (England 1994; Kobayashi 1994; Rose 1997; Pezalla et al. 2012), I was able to reflect about how my assistants projected their own positions into focus group discussions. Although I worried about the experiences of participants being misrepresented due to interpretation differences, I also recognized that having two interpreters provided me with two additional lenses through which to produce knowledge. Since interpreters act as cultural brokers (Liamputtong 2010; Caretta 2015), our qualitative writing can be enriched by the perspectives and verbiage that multiple interpreters can

bring to the qualitative data. For example, Peter's explanatory interpretations, coupled with the literal anecdotal responses as interpreted by Mark, provided deeper understanding of what participants wanted to convey while retaining the context of how they said it. Each member of the research team brings different skills and perceptions to the research process, situated through their own subjectivity and positionality (Turner 2010; see ► Chap. 92, "Researcher Positionality in Cross-Cultural and Sensitive Research"). Explicitly acknowledging the role, identity, and subjectivity of interpreters requires us to recognize and reflect upon the pitfalls and opportunities that finding meaning in interpreted discourse presents.

4 Survey Translation Challenges

Although I did use forward-backward translation of the survey as the most appropriate means of ensuring a "correct" translation, this approach was flawed in that I assumed there was a "correct," equivalent meaning in the local tribal languages and that the words used in the survey would not be filtered by cultural context (Larkin et al. 2007). I had been warned by a zoonotic disease transmission researcher working around Kibale National Park that translations for illnesses would be problematic (Goldberg et al. 2012). For instance, local people call a fever *Omuswija* in both Ratoro and Rakiga, but they also use exactly the same term for malaria. During the first forward-backward translation cycle of the household survey, both the question whether household members had suffered from a general fever in the last 5 years and the question asking about whether household members had suffered from malaria came back translated as identical questions. In the next translation iteration, I added some clarification to the malaria question having the term literally translated as "fever caused by mosquitoes." When we collected survey data in 2009, 98% of respondents claimed household members had experienced malaria in the last 5 years while only 89% said household members had suffered from a general fever. Although the prevalence of malaria seems very high, my study site lies in a high malaria transmission zone of Uganda where almost every household has reported malaria (World Health Organization 2015). As a lesson learned for future surveys, the disease questions will be followed with clarification questions about how the respondent knows someone in the household had the disease, and whether the patient was tested for the disease. This will at least confirm the verified cases, but given the poor access to malaria testing in rural Uganda, the verified cases significantly underestimate reality.

The other problem I encountered during forward-backward translation of diseases was the lack of familiarity of my research assistants with the Ratoro and Rakiga words for certain diseases; although this lack of familiarity did minimize the potential for Peter and Mark to interpret and bias responses based on their own prior experiences (Kapborg and Bertero 2002). Health care research is particularly prone to gaps in conceptual equivalence during translation because medical terms often have no directly equivalent translation in the participant's language (Frederickson et al. 2005). Since it is essential for interpreters to be familiar with all terms being used

prior to starting data collection (Irvine et al. 2007), I asked Peter and Mark to speak with local doctors and nurses to find out how to translate the terms for yellow fever, trypanosomiasis, and tuberculosis among others. However, when we piloted the survey, the pilot respondents did not know what many of the translated disease names meant, demonstrating that the translations provided by medical personnel had no conceptual meaning for local residents. Since I still wanted to collect data on disease load for households near the park, I worked with a medical professional to create picture cards for each disease showing a person and pointing to the symptoms that one would experience in different parts of the body if one did suffer from the disease. This approach was far from medically rigorous, reducing the validity of the data to base symptoms rather than reliably recording self-reporting of specific diseases, and seriously limited what use could be made of the results. To at least partially address this issue of data validity, survey results were triangulated through cross-correlation of diseases within the survey data, and comparison of the proportion of respondents self-reporting the disease with country wide and regional statistics. For example, respondents reporting household members suffered from heart disease and those claiming to have high blood pressure in the household were strongly associated ($\phi = 0.441$, $p < 0.001$), and the self-reported rate of cancer (4.9% of households) was similar to the cancer death rate for Uganda reported by the WHO (5%; World Health Organization 2014).

5 Self-Reported Disease Load and Implications for Conservation Research

Although the original intent of collecting information about household disease was to use the number of diseases self-reported by respondents as a proxy for household well-being, having collected disease data allowed me to check a claim made in focus groups by participants stating they suffered from more illness as a result of living near the park; a claim supported by 95% of respondents in the household survey. Of the 19 illnesses listed in the survey questionnaire (see Fig. 1), respondents reported members of their household suffering on average from 5.6 of those 19 diseases within the prior 5 years (range 0–15).

The number of self-reported diseases, or the disease load, was higher the closer a household was located to the park boundary ($r_{\text{spearman}} = -0.094$, $p = 0.021$). In particular, trypanosomiasis/sleeping sickness (Mann-Whitney $p = 0.043$), tuberculosis (Mann-Whitney $p = 0.026$), and pneumonia (Mann-Whitney $p = 0.094$) were self-reported more frequently closer to the park. Tsetse flies, the carrier of trypanosomiasis, are more prevalent in national parks in sub-Saharan Africa (Gondwe et al. 2009), so higher rates of the disease closer to the park is feasible. However, having used the symptom charts during the survey, and since both pneumonia and tuberculosis result in severe coughing, I believe the tuberculosis and pneumonia results may be more accurately interpreted as pulmonary distress, as many survey respondents commented that the women of the household were suffering from severe coughing. In rural Uganda, cooking is done by women using open fires, often within small huts

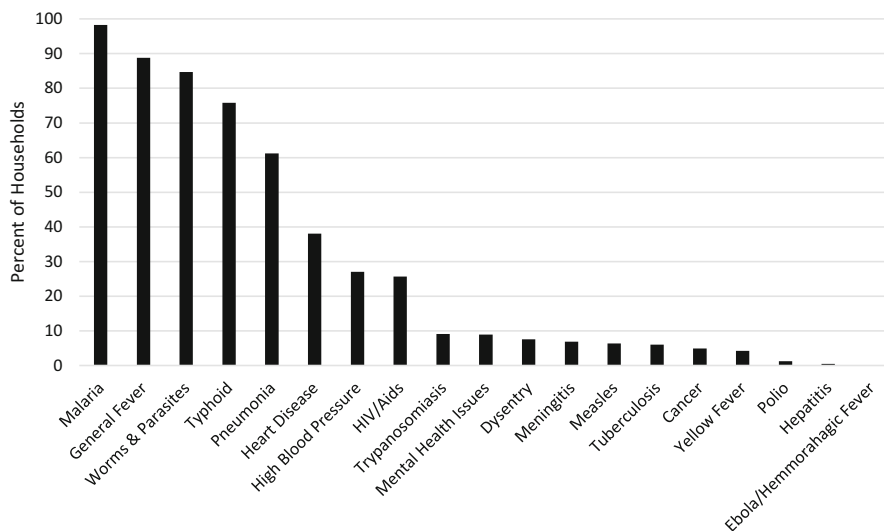


Fig. 1 Self-reported diseases by household respondents around Kibale National Park, Uganda

(Naughton-Treves et al. 2007), resulting in significant smoke inhalation (Wallmo and Jacobson 1998). Much of the rural landscape in Uganda is becoming denuded of trees as people convert land for agriculture (Hartter and Southworth 2009), so trees inside protected areas are becoming a much sought after resource (MacKenzie et al. 2012). The more frequently a household respondent admitted taking firewood from the park, the more likely the household was to self-report pneumonia (χ^2 likelihood ratio = 19.2, $p = 0.002$). Since households closer to the park are more likely to illegally harvest trees from the protected area (MacKenzie and Hartter 2013), this access to firewood may be increasing the cases of pulmonary distress closer to the park as more wood is used for cooking, making bricks, brewing alcohol, and creating charcoal to sell to urban centers (Naughton-Treves et al. 2007; MacKenzie and Hartter 2013). Given the self-reported nature of the disease data, these results are far from conclusive, but they do provide sufficient evidence to warrant future research into the linkage between protected areas and human illness. Providing medical facilities near protected areas may not only be good for improving relations with local communities (Chapman et al. 2015) but may also be needed to mitigate the higher disease load associated with living near a protected area.

6 Conclusion and Future Directions

Although becoming fluent in the language of one's study location is the gold standard for qualitative research, many researchers arrive in a foreign country with little or no knowledge of local languages (Liamputtong 2010). This presents a significant challenge to the research design, as a strategy for cross-language

interpretation must be developed. Ideally, accredited interpreters should be used (Squires 2009; Liamputtong 2010), but often interpreters with the necessary credentials are not available at the study site or research budgets preclude being able to afford accredited personnel. The choice of interpreter may be dictated by circumstance but the researcher may have their own preferences for the interpreter to hold common traits with the interviewees to facilitate the comfort of the interviewee (Edwards 1998), while other researchers believe the best interpreter is aligned with the researcher's background and education (Freed 1988). These two criteria rarely exist in one person in a foreign research context; however, it is important to acknowledge the characteristics of the interpreter and their role during the research process (Kapborg and Bertero 2002; Squires 2009). If the researcher hires local people as interpreters, the researcher must assess the linguistic skill of the hired research assistants, and assess whether the social position or research topic subjectivity of these assistants bias the qualitative and quantitative data collected.

My cross-language research experience in Uganda leads me to recommend testing the linguistic proficiency of the interpreter by having them participate in a forward-backward translation exercise or having a trusted colleague who is fluent in the local language oversee a pilot interview translation to determine if what is being said by the participant is interpreted into the researcher's primary language with appropriate vocabulary, grammar, and cultural context. Both of these approaches have worked well for me as I worked around different protected areas in Uganda where language translation from six different tribal languages into English was required. However, even if the interpreter possesses excellent linguistic and interpretation skills, their social position within the local community, their prior lived experiences, and how they feel about the research topic can filter the discourse and data that the research project is designed to analyze.

As researchers, our positionality and subjectivity are managed by self-critical introspection and constant questioning of how our own personal bias may enter into the interview situation and the interpretation of participant comments. Similarly, this same diligent awareness of potential bias also needs to be conducted by or for the interpreters. Teaching the interpreters about the influence social position and research topic subjectivity can have on data validity needs to be part of the initial training program as the interpreter is introduced to the research project. After the interpreters are made aware of how knowledge is socially constructed and the need to be vigilant for personal biases to creep into the data, the interpreters and researchers can keep and share reflexive journals to understand how their own positions could be projected into interviews and focus group discussions (Caretta 2015). Alternatively, the interpreters can be interviewed to collect information about the interpreter's social position and research topic subjectivity (Edwards 1998; Temple 2002). These interviews can then be analyzed and assessed against the interpreted transcripts to look for potential issues in the data.

The ability to triangulate within the research design adds rigor and validity to the data collected (Baxter and Eyles 1997; Bryman 2016). This triangulation can be done through the use of different data collection methods, the use of different data sources, and in the case of language interpretation, through the use of multiple

interpreters. Although hiring multiple interpreters is an added expense for the project, having the ability to compare more than one translated transcript provides confirmation of interpretation accuracy and can identify issues with paraphrasing, omissions, or elaborations of participant comments. Even if multiple interpreters are used for only a short period of the project, the insight that juxtaposing two transcripts provides can highlight the biases the researcher needs to be aware of for the rest of the project.

The limits that working through an interpreter might introduce to the research project need to be recognized and documented during the publication process. Although early ethnographers often acknowledged their assistants and the cross-language role they played, today it is rare to explicitly see the interpreter in research papers (Temple 2002). Research assistants, and interpreters are noticeably absent from most scientific writings (Sanjek 1993; Schumaker 2001), with only the voice of the manuscript authors visible in the text (Clifford 1983), as if the authors spoke directly with the research participants. A review of cross-language qualitative nursing studies found 85% of the papers did not acknowledge interpretation as a methodological limitation in their study, and only 55% of the papers mentioned that the work was conducted with a bilingual assistant but failed to mention the scope of the interpreter's role or their credentials (Squires 2009). Therefore, the cross-language strategy does not end when data collection is complete, the researcher also has the duty to acknowledge the existence, role, qualifications, and subjectivity of the interpreter in research papers as the project findings go to publication; although I have found this to be a challenge when word count limits what can be included or when editors and reviewers fail to see the value in demonstrating rigor with regard to interpretation.

Ultimately, each cross-language research project is different and the opportunities for improved cultural understanding, local networking, and access to the lived experiences of research participants are far more beneficial than the extra work required to implement a cross-language research strategy to ensure validity of the data collected. However, we as researchers need to be transparent about the challenges introduced by conducting research in a cross-language context, document the strategy used to address these challenges, and broaden critical reflection to include interpreters as we strive to find meaning in both qualitative and quantitative data collected in a foreign language.

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An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups

95

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Contents

1	Introduction	1654
2	Philosophical Approach to the Research	1655
3	Research Team	1656
3.1	Interpreters and Translators	1657
3.2	Preparing Yourself	1658
4	Participant Recruitment	1659
4.1	Informed Consent	1662
4.2	Co-Participants	1663
5	Data Collection	1664
5.1	Interview Guide	1664
5.2	Briefing Interpreters	1665
5.3	Language use during Interview	1667
5.4	Second Interviews	1668
5.5	Confidentiality	1669
5.6	Data Analysis	1669
6	Transcription of Interview Data	1670
7	Reporting Findings	1670
8	Budget	1671
9	Conclusion and Future Directions	1672
	References	1672

Abstract

Language expression and comprehension is fundamental for in-depth research interviews, representing both the data and the communication process by which data are generated. A lack of shared preferred language between researcher and participant creates complexity and additional challenges in the research process, particularly when there are participants from multiple language groups. A

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common solution is to exclude participants on the basis of language preference; yet, there is a need for studies to reflect the diversity of contemporary communities. This chapter introduces a research approach and methods which have been successfully used to conduct in-depth interviews with people from multiple language groups in a constructivist grounded theory study. The approach requires the researcher to be both reflexive and adaptable in their research practice and to develop good relationships with participants and language interpreters. Key strategies are presented for conducting culturally competent and rigorous research in this unique context at modest cost. Adoption of this approach can enable health researchers to take “able to speak English” out of the inclusion criteria of studies and conduct inclusive research with culturally diverse communities.

Keywords

Language · Interpreters · Translation · Interviews · Qualitative · Grounded theory research · Constructivist paradigm

1 Introduction

Including people from multiple language groups in a study when the languages they speak are not determined before starting recruitment is a unique situation in qualitative cross-cultural research. The diversity of the participant sample restricts a researcher’s ability to immerse in a single culture or to have sole reliance on either their own language skills or those of a research assistant. A common solution to this complexity is to only recruit people who are proficient in the preferred language of the researcher; yet, there is a clear need to avoid such exclusionary practice. Qualitative research is increasingly relied on to contribute to the evidence-base that informs health care practice (Sandelowski and Leeman 2012; Liamputtong 2016, 2017; see also ► [Chap. 63, “Mind Maps in Qualitative Research”](#)). The voices that are heard need to be carefully considered as it is often the people who do not share the identity and language of the larger cultural groups in society whose experience is missing from research findings. Yet, it can be these individuals whose voice may be the more important to hear regarding the performance of health services. For example, an important premise of my own study, which I will draw further examples from in this chapter, was to inform the practice of health care after stroke. In a contemporary Australian city, the people who present to hospital for emergency care after stroke are likely to speak one of at least 19 different languages other than English. And so I chose to recruit people with stroke irrespective of which language they preferred to speak.

A second argument to raise here in support of including people from multiple language groups in health research is one of distributive justice. All people should have the opportunity to participate in research that informs the type and quality of services provided to their community so that there is fair distribution of the benefits and burden of research (NHMRC et al. 2007). Yet I challenge that too easily the words “able to speak English” are listed in study inclusion criteria. This practice threatens the equity

of the research process for our society and the credibility of research as a method of informing how contemporary communities do, and can, operate. Hence, why an approach to how it can be different for qualitative research is presented in this chapter.

This justification for inclusive cross-language research practice does not mean it is an easy approach for the researcher to take. Language expression and comprehension is fundamental for in-depth qualitative interviews, representing both the data and the communication process by which data are generated (Hennink 2008; Liamputtong 2010). When participants are from multiple language groups, there is greater complexity and additional challenges in the research process to ensure the quality and trustworthiness of interview data and its interpretation. This does not mean it should not be, or cannot be, undertaken. However, it *does* mean that researchers need to be aware of, and responsive to, related methodological issues (Mabel 2006). In this chapter, I provide guidance for how researchers can successfully navigate such issues to undertake rigorous and ethical qualitative research using interviews with people from multiple language groups when the languages are not determined prior to recruitment. The approach I present is based on my own research experience conducting cross-language research in an Australian metropolitan context and the advice of others from the literature. Each stage of a study is addressed with a pragmatic presentation of the decisions to be made and strategies that can be used. The chapter begins with a brief consideration of the philosophical orientation of studies which aim to include people from multiple language groups, and the chapter concludes with considerations for research budgeting and future directions.

2 Philosophical Approach to the Research

It is the philosophical premises of a study that influence the relationship between the researcher and the participants and the aim of the study (Wuest 2007). Identifying the methodology of the research is important as a foundation to the choice of its methods (Liamputtong 2013). For qualitative research that aims to understand the experience of people who are culturally and linguistically different to the researcher when languages are not determined prior to recruitment, there are four key requirements of the chosen philosophical approach. It needs to be sensitive to the diversity of cultural understandings and communication, provide a way to conceptually recognize the active role of the interpreter within the study, support innovation in methods to achieve a rigorous process in a complex context, and facilitate production of knowledge that is relevant to the study's objective and how others may understand and use that knowledge (Giacomini 2010).

For my study, I chose a constructivist grounded theory approach as a good match to these conceptual requirements (Wong et al. 2017). The inductive nature of grounded theory allows the researcher to focus on the experience and issues of a minority group of people without requiring comparison with a dominant group or using a theoretical framework that may not be culturally appropriate (Dilworth-Anderson and Cohen 2009). Importantly, it supports innovation and flexibility in the research process as researchers are encouraged to choose methods that will answer research questions with “ingenuity and incisiveness” (Charmaz 2006, p. 15). The

approach's social constructionist philosophy conceptualizes each person's reality as constructed within a cultural context of particular historical or social conditions (Charmaz 2015), allowing a person's individual cultural understandings to be explored and recognized in the data. Its pragmatic foundation fosters reflexive questioning of both the participants' and researcher's own standpoints and assumptions about the topic (Charmaz 2009). Importantly, the voice of the participant is afforded power in the process (Temple and Young 2004) as the researcher is positioned as an interpreter of the studied phenomenon, "not as the ultimate authority defining it" (Bryant and Charmaz 2007, p. 52).

From a constructivist perspective, the language interpreter in research is not a neutral conduit of talk but a third active agent in the research interaction producing knowledge (Temple and Young 2004). In keeping with the pragmatist tradition, the interpreter is also considered to bring their past, their perspectives, and their expectations of the situation to the construction of meaning in a research interview (Wadensjö 1998). This is not unproblematic as interpreters make choices in the words they use to convey research participants' meaning. Many interpretations can be judged "correct," but it is the conceptual equivalence, or "essence of the process" (Stern 2009, p. 57), which is integral to grounded theory data and its analysis.

Constructed grounded theories are partial and conditional, situated in time, space, positions, action, and interactions for relevance to contemporary practice (Charmaz 2015). This methodology fits with a culturally sensitive approach that acknowledges culture as dynamic and views all interpretations as provisional. The inductive nature of grounded theory is particularly relevant to gaining understanding in areas where there is little previous knowledge, or when what is known from a theoretical perspective does not satisfactorily explain what is going on (Wuest 2007). Growing migrant populations provide a challenge to the monocultural and monolingual lens of much health care knowledge and so a grounded theory approach can address issues of health care practice with an explicit focus on diversity (Green et al. 2007).

Constructivist grounded theory has also been used in focus group research with people from multiple language groups (Garrett et al. 2008), but it is not the only philosophical orientation for this research context. Other published studies have used interpretive descriptive (Asanin and Wilson 2008; Clark et al. 2014), action participatory (Ellins and Glasby 2016), and narrative (Edwards et al. 2005) methodology. It is for the researcher to decide the philosophical approach which is the best fit to the research requirements as described above, the study topic, and their own values.

3 Research Team

Any research project aiming to recruit people from multiple language groups will need a team of people to provide the primary researcher with expert advice and practical support including language assistance. A mix of perspectives and experiences in the team can benefit the creativity needed to meet challenges in the research process and rigorously ensure that no assumptions go unquestioned. My study's research team included health professionals, a methodology expert, and a language expert.

The research team can support the cultural sensitivity of the research. An advisory group with members of local participant communities can advise the researcher on individual cultural contexts known to them and also more broadly on issues associated with language difference, migration experience, and research participation (Franks et al. 2007; Ellins and Glasby 2016). Although an advisory group may not cover all language groups that are recruited, the demographics of the languages spoken in the community can inform group membership and many aspects of migration experience are shared between cultural groups. Alternatively, a stakeholder group of staff who are experienced working with the population can advise on the conduct of the research process as they will be familiar with the cultural understandings of different groups and aware of communication issues (Clark et al. 2014). These groups may also assist the researcher to access potential participants for recruitment. Another strategy for cultural sensitivity, as used in my study, is to work with language interpreters as members of the research team. Interpreters can act as a type of cultural broker to help the researcher prepare for the interview and to then understand the cultural context of interview data (Dysart-Gale 2005). This role needs to be discussed with each interpreter at the beginning of their research involvement (see Sect. 5).

3.1 Interpreters and Translators

When multiple languages are spoken by participants, it is necessary to work with multiple interpreters and translators. Interpreters enable the shared understanding between researcher and participants for informed consent and data collection in qualitative research (Liamputtong 2010; see also ► Chap. 94, “Finding Meaning: A Cross-Language Mixed-Methods Research Strategy”). All interpretations are situated within the context of the interpreter-mediated interview and the translation memories and histories of the interpreters (Temple and Koterba 2009), so who does the interpretation does matter to the research (Temple and Young 2004). Using the one interpreter per language group aids consistency of interpretations for study rigor (Liamputtong 2010). For my study, I chose to work with professional interpreters who were accredited with the National Accreditation Authority for Translators and Interpreters (NAATI) in Australia, requiring them to abide by a Code of Ethics. Sourcing all professional interpreters from a single agency reduced my workload to negotiate individual arrangements, ensured an interpreter would be available for the majority of languages likely to be spoken by participants, and I was able to develop a relationship with the manager to request interpreters who were experienced in health care terminology and contexts which I would be discussing with participants.

Some participants may prefer to use a family member or friend to interpret for them as often occurs during health care (Alexander et al. 2004; Schenker et al. 2011; Fryer et al. 2013). It is well documented that miscommunication is more likely to occur in interpreted health care conversations when untrained interpreters are used (Flores et al. 2012). However, informal interpreters can provide qualities of personal trust, familiarity, and comfort which can be lacking in professionally interpreted interactions (Alexander et al. 2004; Gray et al. 2011). In my study, I encouraged the

presence of family members during the informed consent and interviews with professional interpreters to help the participant feel comfortable and supported during their research involvement (see Sect. 4.2).

Translators facilitate written study information to be available to participants from multiple language groups. For my study, I chose to use accredited professional translators listed on the website of the Australian National Accreditation Authority for Translators and Interpreters (<http://www.naati.com.au>). The use of a national accredited online source widens the pool of translators available to do work in a timely fashion (within five days). Direct communication between the translator and researcher via email or telephone allows the researcher to introduce the study purpose, clarify the key concepts to be communicated by the flyer, and answer any questions. It also allows the individual translator to set their own competitive fees which can benefit the research budget.

3.2 Preparing Yourself

The findings in qualitative research are influenced by the researcher's questions, choices, and strategies in the research process and so are inseparable from the researcher's perspective (Charmaz 2015). Therefore, it is important for the researcher to prepare themselves for the culturally sensitive approach needed in this research context and to interrogate their research choices (Finlay 2002). When the languages spoken by participants are not determined before recruitment, the researcher cannot be expected to gain thorough knowledge of each participant's cultural group. Yet, the research still needs to be sensitive to each participant's cultural understandings, values, and communication for both ethical and rigorous research practice (Liamputtong 2008, 2010). Developing cultural awareness begins with a person recognizing their own cultural values and understanding that the possibility of cultural difference between researcher and participants is not isolated to comparisons of language; culture is a dynamic concept which refers to meanings built on contemporary and historical legacies, social systems, and discourses, acting as a framework for the interpretation and agency of people at different times and in different contexts (Mallinson and Popay 2007; see also ► Chap. 88, "Culturally Safe Research with Vulnerable Populations (Māori)"). Cultural competency training can support a researcher in their development of culturally sensitive research skills; there may be workshops available locally through health care organizations or via online modules. I attended to cultural sensitivity and reflexivity in my study by examining my own background, standpoints, and values in field notes and analytic memos, then discussing this reflexive examination with my research team, and including my position regarding the study topic in research reports. I also attended a local workshop on working with interpreters in health care.

To conduct the research approach as I have presented in this chapter, a researcher needs to become competent in working with interpreters. Conducting a research interview with an interpreter is pragmatically similar to a health professional conducting a patient assessment with an interpreter. Both contexts require specific

attention to role preparation, introductions, positioning, and style of interpreting. There are many excellent resources to guide health professionals in the skill of working with an interpreter which are also useful to researchers, for example, the Interpreter information sheets available from the Australian Institute of Interpreters & Translators (<http://www.ausit.org/>) and Centre for Culture, Ethnicity and Health (<http://www.ceh.org.au/>). There may also be local training available. The key is to practice new interview skills prior to commencing data collection (see Sect. 5).

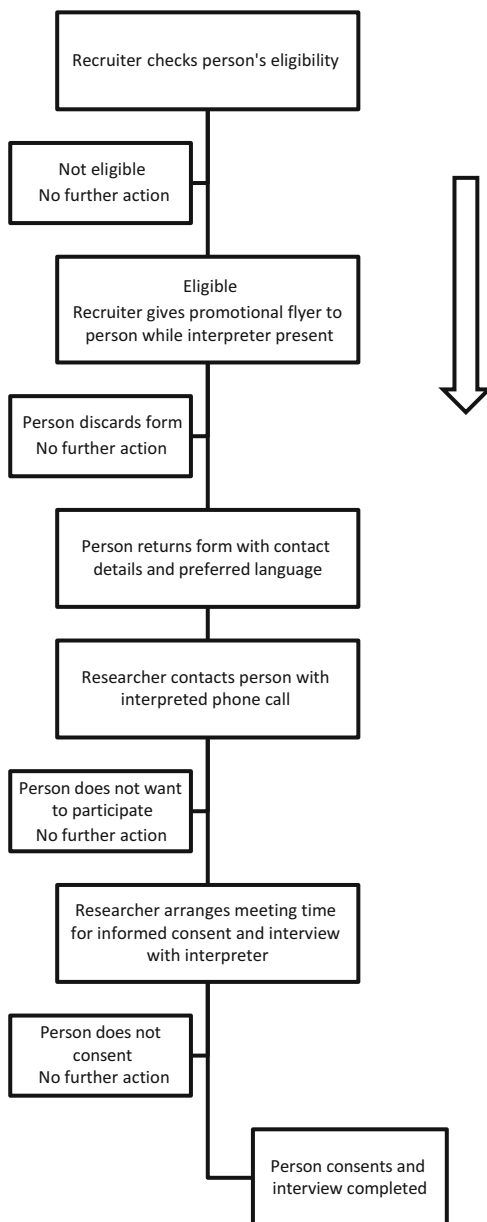
4 Participant Recruitment

The recruitment pathway for the cross-language study approach discussed in this chapter needs to accommodate for not knowing the language of participants prior to recruitment. Using a person's preferred language for recruitment is important to convey to them that the study wants to include them (Feldman et al. 2008) and to ensure that informed consent is conducted appropriately (Liamputtong 2008, 2010). Engaging recruiters who are known to potential participants can help recruitment (Liamputtong 2008, 2010). Some studies have used bilingual people working within a health care service or community organization to assist recruitment (Asanin and Wilson 2008; Clark et al. 2014). I achieved successful recruitment of older people from multiple language groups with the help of English-speaking health professionals and the strategic involvement of professional translators and interpreters. The recruitment pathway for my study is given in Fig. 1. The health professional recruiter spoke to the participant about the study and gave a promotional flyer to potential participants during a normal care interaction when the interpreter used by that person was present, either a professional interpreter or an informal interpreter such as adult family or friend.

Promotional flyers can be a useful way to advertise for study recruitment and collect contact details from potential participants. They can be translated prior to recruitment only if the languages are known for the community being sampled from and it is affordable for the study. If this is the case, the flyer can be advertised in language-specific newspapers, displayed at social meetings in the target communities, or distributed by recruiters. Alternatively, flyers can be translated on an "as needs" basis if potential participants are identified early in a window of recruitment opportunity. This second option was suitable for my study that was conducted on a limited budget and recruited from a community of more than ten language groups. When a potential participant was admitted as an inpatient to a recruitment site, the staff notified me what language they spoke. I then arranged for translation of the study's promotional flyer by professional translators (see Sect. 3). Translation of the flyer is needed only once for each language as it can then be copied and re-used for recruitment of other people who prefer to speak the same language.

For translation of the same promotional flyer to many languages, it needs to be of simple design and terms yet meets requirements of Human Research Ethics committees. An example of a flyer is shown in Fig. 2. It is likely, and to be encouraged, that a person with limited English proficiency will want to discuss their potential involvement in the study with people they know and trust, usually the same people who assist

Fig. 1 Example of recruitment pathway



them with English language documents from official sources such as government organizations, banks, and so on. The recruiter will, therefore, need to provide both English and translated versions of the flyer to potential participants so that the literacy of the person is not assumed and the information can be shared with family or friends who may speak but not read the person's preferred language (Irvine et al. 2008).

**How do people who have trouble speaking English
experience the move from hospital
to home after a stroke?**

If you...

- have been in hospital after a stroke AND
- have any difficulty speaking or understanding English AND
- are 60 years or older

We would like for you to take part in this study.

The study will involve you speaking with a researcher for about one hour on two occasions with an interpreter present. All responses will be confidential. Taking part is voluntary.

If you are interested in taking part in this study and would like more information, please complete the form below and give it to your hospital physiotherapist or post it to us in the attached envelope (no stamp needed) or ring the researcher xxxx on ph. xxxx.

I (insert name) am interested in taking part in this study. I agree to the researcher mailing me more information and ringing me when I return home so they can discuss the study with me.

Contact phone

number.....

Contact mail

address.....

I prefer to speak.....language

Fig. 2 Example of promotional flyer

When contact details are returned on the flyer, an interpreted phone call in that language can be used by the researcher to establish if the person is still interested in participating, that they meet the inclusion criteria, and to answer any questions about the research. Some people in my study preferred the initial contact to be made with an English-speaking family member on their behalf. A convenient time to meet for informed consent and the research interview can be arranged if the person chooses to be involved, and the researcher can ask if the person has any preferences regarding the professional interpreter to be present, such as dialect or gender. For the interpreted phone calls in my study, I used a commercial provider of interpreting as the conversations were brief (less than 10 minutes) so costed at a minimum rate

and did not require me to prepare the interpreters for research involvement beyond introducing the study and purpose of the conversation.

4.1 Informed Consent

Informed consent in cross-cultural research has been described as a “thorny subject” (Liamputtong 2008, p. 3) and is often poorly reported in research publications (Fryer et al. 2011). If a person’s preferred language is not used during the informed consent process, then it cannot be certain they are fully informed and able to make good choices about their participation (Hunt and de Voogd 2007). The potential for misunderstanding during recruitment and consent also has implications for the credibility of collected data as the words participants use and the stories they tell in interviews are influenced by their relationship with the interviewer (Mishler 1986). The Australian National Statement on Ethical Conduct in Human Research requires researchers to provide study information in the participant’s first language (NHMRC et al. 2007; see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”).

Study information sheets can be lengthy and detailed documents to meet the requirements of Human Research Ethics committees and are, therefore, an expensive document to translate in written form. Such costs can be prohibitive in a study when many language translations will be required. An alternative is verbally communicating study information. A professional interpreter is already present at the arranged meeting between the person and researcher in the described approach, to assist with the interview if it proceeds. Verbally communicating study information addresses potential issues of illiteracy (Liamputtong 2008, 2010) or reading difficulty associated with a health condition, such as stroke. The researcher will also need to provide written study information in English so that it can be shared with family members or friends of the participant who do not share literacy in the person’s preferred language.

The formality of consent procedures can be intimidating to people from cultural and linguistically diverse backgrounds (Liamputtong 2008). The only time when a participant was obviously hesitant during the informed consent process in my study was when an interpreter read the information sheet in a formal manner straight from the printed document rather than consecutively interpreting me, as researcher, speaking the information. It was obvious from this experience that providing study information in a conversational format between researcher and participant, with discussion and questions in their preferred language, is a more sensitive and individualized process. This discussion can incorporate a teach-back or teach-to-goal approach by the researcher (Kripalani et al. 2008; Sudore et al. 2006) to ensure the person understands what is being asked of them and why.

The consent form is a shorter document than the study information sheet, and ethics committees usually require they are in a written form in the participant’s preferred language. The translation of consent forms can be arranged after the phone call to the participant, working with the same translator as for the promotional flyer.

Staggering translations in this way ensures limited research funds are not lost if a person declines to participate. The written translation of each consent form can be “checked” prior to its first use by the professional interpreter assisting with interviews in that language, see “Interpreters” for further discussion. The consent form can also be read aloud by the researcher with consecutive interpreting in case of literacy or reading issues, and several participants in my study accepted this offer.

4.2 Co-Participants

Family members often accompany people with limited language proficiency to health care appointments. Participants from all language groups in my study appeared accustomed to and comfortable with the presence of their family during the research interviews. Sometimes the family member sat quietly in the background to listen or moved in and out of the room completing household tasks. Others were more involved in the interview, mostly to assist the researcher to understand an aspect of the participant’s story. For one couple, it was obviously an accustomed way for them to tell a story together (Box 1). And when the frailest participant in the study fatigued, his two sons continued to talk about their father’s experience while he remained in the room listening to them. Including family members as co-participants in the qualitative research is an example of a response to a culturally sensitive situation encountered by a researcher in the cross-language context (Liamputtong 2010).

Box 1 Example of participant and co-participant telling a story together

Interviewer (English): Is that the wife who’s a nurse?

Rosa (English): Yes, yes. She’s English.

Gino (English): Actually, that’s end nurse, was a nurse but now a boss.

Rosa: A big boss now.

Interviewer: But now a boss?

Rosa: In a nursing home.

Interviewer: In a nursing home, ok.

Gino: She do just three days a week something.

Rosa: Not much now, before work more but now stopped.

The term “co-participant” recognizes that the self-selected contribution by family is part of the participant’s story and not a separate one. In my study, these “co-participants” were not purposively recruited so there was not a planned recruitment strategy for this group. Rather than disrupt the co-operative story telling during the interview, I waited until the interview had ended to conduct informed consent with co-participants. However, researchers interviewing people who prefer to speak another language may anticipate the preference for a family member to be present and proactively consent these co-participants.

Table 1 Interview protocol

When	Researcher actions
Prior to interview	Develop own awareness of language and cultural group of participant Prebrief with professional interpreter Complete informed consent
During interview	Encourage participant to speak language as they wish Follow interview guide Work with a professional interpreter to seek clarification if needed Digitally record interview
Immediately after interview	Debrief with professional interpreter Record field notes
Second interview	Check interpretation of meaning from first interview Introduce emerging concepts from analysis
Immediately after second interview	Debrief with professional interpreter Record field notes

5 Data Collection

The credibility of collected data is influenced by the participant's relationship with the interviewer (Mishler 1986). This can be challenging across a language gap. It takes time and effort to establish a rapport with participants to encourage them to share their experiences (Shenton 2004). A good relationship between researcher and participant can be facilitated by giving the participant the choice of interview location and time (Liamputtong 2010, 2013). In my study, all but one participant chose to be visited at home and interviews were conducted in the living room or around the kitchen table. I also spent time in conversation with participants and their family, often over a cup of tea or coffee and looking at cherished photo albums. A token of appreciation for the person's participation was always given. Following consultation with the interpreter about appropriateness of the gift, all participants were given either cholesterol-free almond bread or summer fruit.

The protocol for interviews in my study is shown in Table 1 and explained in the following sections.

5.1 Interview Guide

Semi-structured interviews which aim to explore each participant's experience have an open format with some preplanned questions, relying on the interviewer to follow up on participant's answers and to probe for more information to gain rich data for analysis (Kvale and Brinkmann 2009). It is usually expected that the participant will relate their experience to the interviewer in a narrative format. The idea of a set narrative structure may be variable across language groups and therefore, not appropriate for all participants in this cross-language research context (Temple and

Koterba 2009). Interview guides can encourage participants to choose the structure of how they relate their experience and allow the participant to identify what is important to them in their story. Cues can be used to prompt the participant where to locate its start, but this may not always be needed or appropriate. Probes can then be used by the interviewer to extend the participant's response or to draw out and understand specific parts of their experience. In Box 2 is an example of the interview opening and a probing question used in my study.

Box 2 Example of interview opening and probing question for participant

Interview opening:

Now, I'm going to ask you to tell me about what happened after your stroke, right up to being here at home today. I want you to just keep talking in your own time and I will listen. I'd really like to hear your story. Later I may ask you a few questions, but for now I'll just listen to you. *(optional: So, when did you have your stroke?)*

Probing question:

Can you tell me what it is like for you when the doctor talks to your son and cannot talk to you?"

Drafting of a semi-structured interview guide can begin by the researcher looking at published interview guides from instructional texts or published papers in the topic area and then using practice and pilot interviews to develop a final interview guide. If the researcher is new to qualitative interviewing, practice interviews conducted in their own preferred language are invaluable to gain confidence in interview skills such as phrasing, intonation, sensitive listening, as well as digital recording. For the specific research context of this chapter's approach, it is essential for the researcher to also be practiced in conducting interviews with an interpreter present.

In practice interviews with an interpreter, the researcher can trial the positioning and timing of asking interview questions with interpreting and the success of probes in a cross-language context. Pilot interviews with people from the population to be studied are then important to check the appropriateness and usefulness of the interview guide for the topic; that it gains the data that the researcher is seeking. It is not possible to pilot the interview guide with all language groups and interpreters in the context of not determining languages prior to recruitment, and so pre-brief sessions with professional interpreters are important to achieving sensitivity and rigor of the interview process.

5.2 Briefing Interpreters

Interpreters need to be prepared for their role in the research (Kosny et al. 2014). A "pre-brief" meeting before their first interview facilitates a shared understanding of

the study purpose, the aim of the interview, how the interview will be conducted, and the anticipated role for the interpreter (Hennink 2008). Copies of the study information sheet, consent form, and interview guide can be shared and the interview guide can be reviewed for any anticipated translation difficulty. For cultural sensitivity, the interpreter can be asked for any insights into appropriate communication and conduct during interviews with a person from their language group. In my study, pre-brief meetings were scheduled with each interpreter for one hour duration approximately a week prior to their first interview.

Real-time interpretation allows each participant to use a language they are proficient in and allows the researcher to hear the interview dialogue as it occurs and to intervene to clarify responses or to rephrase questions at the time of the interview. Data analysis can be started by the researcher directing new questions while data are being collected (Larkin et al. 2007). Consecutive interpreting works well when participants are relating experiences in interviews. In this mode, the interpreter waits for the speaker to finish talking for a reasonable length of time before interpreting it. The idea of conceptual equivalency in the interpretation rather than word equivalence is important for qualitative interpretive research (Liamputtong 2010). This can be achieved by asking the interpreter to actively select words or phrases to convey the meaning as presented by the participant to the researcher, rather than a direct translation of words used (Larkin et al. 2007). A way to explain this in a pre-brief meeting is given in Box 3.

**Box 3 Explanation of interpretation method sought for interviews
Researcher to interpreter:**

I recognize and appreciate how important your interpreting skills are in helping me to gain useful and accurate information from the interview. As I do not speak a second language, it is important for this research that I understand the ‘idea’ of what the participant is telling me – what meaning they give to events that happened and how it made them feel. I realize this may sometimes be challenging to achieve but I hope we can work together to gain a good understanding. Today I will read through the planned interview questions with you and discuss their translation to the preferred language of the participant. I would also appreciate any advice you have for successful interviews with people from this cultural background.

The “pre-brief” meeting is also useful to explore each interpreter’s experience and perceptions of the research topic. In my pre-brief with each interpreter, I asked them about their perspectives on the research topic; their experience with healthcare interpreting work; if they were from the same community as the participant; and how they related to or perceived the participant’s community (Hennink 2008). A few interpreters closely identified with the study through personal experiences with relatives who had suffered a stroke and this allowed me to question in debriefs how the participant’s experience differed from

their own. Another interpreter had a strong belief that the Australian healthcare system was much better than health care in his country of birth, and we spent time at his prebrief and in debriefs discussing its relevance to the experiences being reported by participants.

A debrief after the participant interview is useful to get feedback from the interpreter on the interview conduct and management of the discussion, for example, how they perceived the ease of the participant in answering questions or any difficulties noted. The researcher can also give the interpreter feedback on their role in the discussion and discuss possible interpretations of the participant's data as explained above. Clarification can be sought for any phrases or cultural references in the dialogue that remain uncertain for the researcher. In my study, this included historical information as background to the participant's reported migration or work experiences. Record all briefing discussions in field notes to refer to during data analysis.

5.3 Language use during Interview

Not all participants will want to use their preferred language during research interviews (Liamputtong 2010). Many of the participants in my study prided themselves on their ability to converse in English and wanted to demonstrate this ability to the researcher. Even the participants who reported speaking English "not well" used occasional English words. This "code-switching" between languages is well documented for native/non-native speaker interactions (Holmes 2001). I introduced the interpreter at the start of the interview as described in Box 4 to give participants control over the language they used to tell their story.

Box 4 Encouraging participant to decide language use

Interviewer to participant:

(Interpreter name) is here today to help us by interpreting our talk. I am also happy for you to speak in English at any time if you wish to. (Interviewer, English).

When participants from different language groups speak in English, their speech will often have grammatical and pronunciation differences to the researcher's speech. Professional interpreters can help to interpret accented English talk that is difficult for the researcher to understand as explained in Box 5. Another strategy a researcher can use is to repeat the sentence back to the participant for them to confirm the accuracy of understanding. If still unsuccessful, a researcher can apologize for their difficulty in understanding and respectfully ask the participant to repeat the information in their preferred language so that the interpreter can communicate their meaning to the researcher.

**Box 5 Explanation for interpreters about participant language use
Researcher to interpreter:**

During the interview the participant can choose how much or little they wish to speak their preferred language. Sometimes it is difficult for me to understand English spoken with an accent. If I am unsure of a term or phrase, I will ask for your help to clarify it.

For participants who decline an interpreter, it can be a greater challenge for the researcher to understand their accented speech and may necessitate frequent requests to repeat or clarify talk. This is a sensitive but essential balancing act between interrupting the flow of the interview conversation and ensuring a good understanding of the participant's meaning (Marshall and While 1994). The researcher must then record extensive field notes of the conversation after each interview to refer to during transcription of the interview talk.

5.4 Second Interviews

Second interviews are an important tool for the credibility of the data analysis when researchers do not share the same preferred language as the participant. Second interviews allow the researcher to check with the participant that they have interpreted and understood the meaning of an experience as the participant intended. This is not always a straightforward task in the context of interpreter-mediated talk but was a successful strategy when used with sensitivity in my study as demonstrated in the example in Box 6.

Box 6 Example of use of second interview to check researcher's interpretation of data

Interviewer (English): Last time you told me you liked to have help in Greek, in case you answered wrong and you might damage yourself.

Andreas (Greek): I don't know if I have said that. That is the first time I have heard this because when I have an interpreter there, the interpreter tells me, I answer properly. I never said that I made a mistake, that I said this.

Interviewer: I think you meant that you were concerned that if you did not have an interpreter you may answer something wrong. Is that right?

Andreas: That's it, that's what I was thinking. Then they will think, "What is he talking about? He can't go home." Just keep me in.

Second interviews also allow the researcher to ask more focused questions about the topic and gain a thicker description of aspects of a participant's experience that are important to emerging concepts in the analysis (Charmaz 2006). A question I introduced to explore how the involvement of an interpreter is decided during health care is given in Box 7.

Box 7 Example of focused question in second interview

Interviewer to participant:

I'm interested in how you decide when to get help with language during your health care. So, when you are going to be talking with someone about your stroke, say a doctor or a nurse or a physio, how do you decide if you need help to understand?

5.5 Confidentiality

Confidentiality of participant data is an important part of responsible research conduct (NHMRC et al. 2007), but often causes dilemmas in practice for qualitative researchers (Lahman et al. 2015). While the researcher needs to de-identify data to minimize the potential risk of harm to the participant, enough identified data need to be kept for integrity of the research and its transferability to communities. For example, the age, gender, and language spoken by participants were reported in my study to situate the experience of the participant for readers of the research. However, I anonymized other characteristics such as their place of residence, type of stroke, and site of recruitment. I also gave participants the opportunity to choose a pseudonym. When a participant was unable to provide a pseudonym, the professional interpreter and I chose a name that we believed to be appropriate to the participant's cultural background (Lahman et al. 2015).

Another strategy to protect participant confidentiality in cross-language research is to use professional interpreters who have their own code of ethics. Professionalism is particularly important if the interpreter comes from the same small migrant community as the participant; on a few occasions in my study, the interpreter and participant recognized each other from a previous job or a shared church community. Confidentiality statements can be used to explicitly establish expectations with the interpreter; however, I suggest that the use of such statements is more to satisfy an ethics committee than what is needed when working with a professional group.

5.6 Data Analysis

A particular issue for credibility in qualitative research when participants speak multiple languages is how to analyze data (Liamputtong 2010). An ideal solution would be to employ bilingual analysts for each language group, but due to cost and availability this is often impractical. The compromise reached in my study with

seven different languages spoken by participants was to analyze all data from transcriptions of the professional interpretation of the interview. Therefore, all data analysis was in English. This method of analysis has been demonstrated to produce the same major conceptual categories as when data are analyzed in the participant's spoken language despite some minor differences in text (Twinn 1997). It is also supported for a grounded theory methodology as it is the meaning rather than the grammar of the interview data which needs to be understood correctly (Stern 2009). The method does rely on successful conduct of the interview using conceptual equivalency in interpretation as described in "Data collection."

When data are analyzed in the language of the researcher rather than the participant, the credibility of the data analysis needs to be confirmed. One way to do this is by taking study findings back to the field (Adamson and Donovan 2002) as occurred with second interviews in my study. Emerging ideas from the analysis were also explored with participants in second interviews to check the "fit" with their own experience (Charmaz 2006). Regular discussions about the analysis with an advisory or supervisory group, modeled on a group process used by Van De Weyer et al. (2010), can sensitize the analysis to different nuances in the data and the possibilities for alternative interpretations. Field notes made by the researcher during data collection, such as participant behavior and feedback from the interpreter, can also assist with the interpretation of meaning during data analysis.

6 Transcription of Interview Data

Data transcription is a time-consuming task in research that cannot always be completed by the researcher alone. In my study, I chose to use a professional transcription agency for interview transcriptions. By using a single transcription agency, I was able to establish a relationship with the manager so that she gave my work to more experienced transcribers and matched familiarity with language if possible. Accented speech is often charged at a higher fee to standard interview transcription and this needs to be acknowledged in research budgeting. Transcribed data will need careful checking by the researcher due to the difficulty that transcribers experience with accented English. The researcher can use their memory of the interview and detailed field notes to assist with corrections, but there may still be words or phrases that cannot be understood. These can be followed up at second interviews with participants, or the uncertainty acknowledged on the interview transcription omitting the unclear data from the analysis.

7 Reporting Findings

Open recognition of the decisions made during the research process and the preferred languages of participants is important to the integrity of the research when multiple languages are spoken (Temple 2006) yet is often missing from research reports (Fryer et al. 2011). Strategies to recognize the language in which data were

spoken and enable transferability of findings in this research context include reporting the language profile of the community the sample is drawn from; each participant's preferred language and language of interview; the language of analysis and explanation of why it was used; and the language in which words were spoken when quotes of data are presented (Box 8). The active role of interpreters and translators can be recognized by including a description of their influence and involvement, as demonstrated in Fryer et al. (2013).

Box 8 Examples of how to report language quoted data was originally spoken in
Quote incorporated within text:

As Thao explained, *"It just happened out of the blue"* (Vietnamese).

Quote separate to text:

"I do because I want to do well. I want to rehabilitate myself" (Gino, English).

Quoting an excerpt of conversation:

Ming (Cantonese): *There's a long corridor, and the nurse go to me, 'Walk.'*

Interviewer (English): *Why did she ask you to do that?*

Ming: *I don't know. Exercise [pause], but I just want to.*

Research findings also need to be shared with study participants and co-participants. This can be achieved by providing a plain language summary of the findings translated to each participant's preferred language, with an English language copy of the summary to share with family who may speak but not read the person's preferred language.

8 Budget

One of the challenges of conducting qualitative research with people from multiple language groups is achieving rigor on a tight budget. The involvement of multiple interpreters and translators can add significant costs. To be financially capable of optimal practice, researchers must provide an estimate of these costs in funding proposals and funding bodies need to recognize that the costs are legitimate and necessary to enable research participation for an often excluded population (Bustillos 2009). When the languages spoken by participants are not determined prior to recruitment, estimates of required resources can be made using the language profile of the population of interest. Being familiar with how interpreting and translating services can be sourced and charged including minimum costs and cancellation fees, helps the researcher to use them efficiently. Resources to be costed for the research approach presented in this chapter include pre-brief with each interpreter; interpreted phone call to each participant; two interpreted interviews with each participant; debrief time with interpreter after each interview; and translation of promotional flyer, consent form, and summary of research findings for each language group.

9 Conclusion and Future Directions

The aim of this chapter is to communicate the importance and achievability of conducting qualitative research with people from multiple language groups, particularly in the context of participant languages not being determined prior to recruitment. The nature of multicultural societies is that health care providers work with people from many different language groups. Research that informs contemporary health care practice therefore needs to respect and reflect this cultural diversity both to be useful and for the fair distribution of its burdens and benefits across communities. The approach to cross-language research presented in this chapter relies on the researcher's ability to be culturally sensitive and reflexive, from the selection and preparation of the research team through participant recruitment, data collection, and analysis, and reporting of research findings. It is an approach that requires both flexibility and creativity in research methods to adapt to culturally sensitive situations, including accommodation to different language preferences of participants through all stages of the research process. Multiple languages spoken by participants require the researcher to develop good working relationships with multiple interpreters and translators using communication in face-to-face, email, or telephone formats. Pre-briefing and debriefing with interpreters is essential to ensuring a trustworthy shared understanding between researcher and participant. Finally, publication of completed studies is encouraged as acceptance and broader application of cross-language methodology will only be strengthened by more published examples of rigorous and cost-effective studies. It is hoped that this chapter encourages researchers to take cross-language research out of the "too hard" basket and progress an ethical and inclusive research agenda that reflects the contemporary communities we, as health researchers, seek to benefit.

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The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research

96

Sara Stevano and Kevin Deane

Contents

1	Introduction	1676
2	Research Assistants: Necessary to the Research Process?	1677
2.1	Who is the Research Assistant?	1677
2.2	How to Assess When Research Assistants Are Needed	1678
3	Working with Research Assistants	1680
3.1	An Employment Relation: Recruiting Research Assistants	1680
3.2	Research Assistants' Tasks	1684
4	Conceptual and Ethical Issues	1686
5	Conclusions and Future Directions	1688
	References	1689

Abstract

Cross-cultural research frequently involves working with research assistants to conduct data collection activities. Due to the range of different functions that research assistants end up fulfilling, from translator to guide to gatekeeper, it is clear that their participation in the research project has implications for the quality of the study design, its process and outcomes. However, their role is not always explored. Drawing on our own research as well as that of others, this chapter discusses a set of key practical decisions researchers need to make when planning their fieldwork – from assessing whether a research assistant is needed to managing a work relation. We show how these practical considerations are

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intertwined with the power asymmetries rooted in the employment relation between researcher and research assistant. We also explore how the triangular power dynamics between research participants, research assistants, and researchers influence the research process and outcomes, as well as how these power dynamics reflect the broader institutional research landscape, in which questions of power, ownership, and extraction are prominent. Researchers need to reflect, discuss, and write more on this topic to fulfil a crucial gap in the literature on research methodology, to provide practical guidance for future researchers, and to identify the basis for fairer collaborations between North and South research institutions.

Keywords

Research assistants · Qualitative research · Social science · Development · Fieldwork · Africa

1 Introduction

Qualitative research in the social sciences is often reliant on the work of research assistants, even more so when it is conducted in lower income countries and cross-cultural settings. Whilst anthropological, ethnographic, and feminist literature has historically been more open to the interrogation of the role of research assistants in the research process and potential influences they may have on the quality and integrity of data collected, in general this is a topic that remains underexplored. The literature on research assistants in qualitative primary research is conspicuous in its absence from most social science qualitative research handbooks (e.g., Ritchie and Lewis 2003; Flick 2009; Silverman 2013; Merriam and Tisdell 2015), with a few exceptions such as Devereux and Hoddinott (1992) and Liamputtong (2010, 2013). Therefore, researchers have very little practical guidance on how to find, recruit, train, and work with research assistants, and the range of associated ethical, conceptual, and theoretical issues that this entails. Further, graduate methodological training frequently overlooks this issue, and as Middleton and Cons (2014), p. 282 note, “for even the most established scholars, the subject of research assistants can make for uncomfortable conversation.”

Drawing on the thin but growing body of work on this issue, as well as our own experiences of conducting fieldwork in a low-income and cross-cultural setting, in this chapter we set out the practical steps researchers go through when they plan their fieldwork and work with research assistants. We show how these practical considerations are intertwined with the power asymmetries rooted in the employment relation between researcher and research assistant. We also explore how the triangular power dynamics between research participants, research assistants, and researchers influence and shape the research process and outcomes, as well as how these power dynamics reflect the broader institutional research landscape and the political economy of research more generally, in which questions of power, ownership, and extraction are prominent.

Whilst all research projects that require the employment of research assistants will face common challenges, it is also clear that the role and influence of research assistants will also be shaped by the specificities of each project. Without a concrete set of guidelines that can be mechanically followed, in this chapter we provide a number of examples designed to illustrate how these issues have been considered by different researchers. We hope that this chapter will aid researchers at all levels of experience in the fieldwork process, as well as to stimulate much-needed further discussion and exploration of the role of research assistants.

2 Research Assistants: Necessary to the Research Process?

2.1 Who is the Research Assistant?

Working as a research assistant may refer to a variety of roles and associated tasks, depending on the context in which the job is performed. Research assistants in academic and nonacademic institutions are often employed by more senior colleagues to carry out desk-based tasks such as background literature searches, annotated bibliographies, and the like (Molony and Hammett 2007). In this area of research, research assistants locate, read, and review *secondary* literature and data.

A rather different role is performed by research assistants who facilitate processes of *primary* data collection. First, the implementation of large-scale surveys relies on the work of interviewers or enumerators who are normally recruited locally, where the survey is to take place, and trained by experienced researchers. As large-scale surveys are the most widely used instrument for the generation of data on household welfare, poverty, health, employment, and so forth, there is some material on training enumerators (Grosh and Glewwe 2000; Iarossi 2006). Most manuals for the implementation of large-scale surveys contain guidance and procedures on the recruitment, training, and supervision of enumerators and instructions on how to ask questions and fill out the questionnaires (see IFC Macro 2009 for an example of this in relation to the implementation of Demographic Health Surveys). Nonetheless, the literature concerned with understanding the *power* of interviewers/enumerators in shaping the process of quantitative data collection as well as its outcomes remains very limited (Randall et al. 2013; Flores-Macias and Lawson 2008).

Second, research assistants can be interpreters. Interpreters provide translation in the course of research activities and are needed in all cases when researchers are not fluent in the language spoken by the participants. There is some literature on interpreters mostly reflecting on how to make translation work in order to collect meaningful data (Temple and Edwards 2002; Temple and Young 2004; Bujra 2006; Liamputtong 2010) and, even thinner material on the relative benefits of different interpreting techniques (Williamson et al. 2011; MacKenzie 2016). However, some argue that the role of interpreters is rarely explored in the literature as the researcher claims and maintains full ownership of the research process and outcome (Berman and Tyyskä 2011) (see also ► Chap. 95, “An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups”).

Third, research assistants facilitate and mediate data collection in qualitative research, which is the focus of this chapter. Many researchers conducting qualitative research in a variety of disciplines, ranging from anthropology to political economy, rely on research assistants to carry out their fieldwork. Whilst initially regarded as interpreters and “conduits” in the research process (Freed 1988), this view has been abandoned thus enabling the expanded role that research assistants in reality play, especially in cross-cultural settings, to be acknowledged. Research assistants tend to be familiar with the context and local language(s) where research takes place and accompany the researcher through interviews and other research activities, either leading the activities themselves or assisting the leading researcher (Deane and Stevano 2016). Research assistants may contribute to the design of research activities prior to their implementation, through informing the selection of research site(s) and participants, as well as the type, structure, and content of interviews or other activities such as focus groups or participant observation (Deane and Stevano 2016). A research assistant also takes part in the ongoing analysis of the material collected through regular discussions with the researcher, an important but often unacknowledged form of informal analysis, giving researchers the space and opportunity to think through and articulate emerging themes and narratives. This expanded role of the research assistant, therefore, requires a more detailed understanding of how they influence data collection activities and the quality of data collected.

2.2 How to Assess When Research Assistants Are Needed

When planning their fieldwork, one of the first decisions researchers are to take is whether they will need the support of one or more research assistants. The most immediate aspect that ought to be considered in this respect is the degree of knowledge, familiarity, and insiderness the researcher has with the studied context, and whether working with a research assistant can facilitate the process of data collection. We suggest a set of key guiding questions that can help researchers making this assessment.

First, the most important questions revolve around the position of the researcher vis-à-vis the research participants. If the researcher is, or is perceived to be, an outsider in the setting where research takes place, then a research assistant with a greater degree of insiderness can help bridge important gaps. These can include the researcher’s lack of institutional contacts as well as her or his limited ability to verify the accuracy of the information collected, linguistic and cultural barriers, and respondents’ uneasiness to speak to an outsider (Liamputtong 2010; see also ► Chap. 92, “Researcher Positionality in Cross-Cultural and Sensitive Research”). It is, however, important to consider that being an outsider has advantages too and researchers may find that in some contexts respondents are more comfortable giving information to an outsider (Liamputtong 2010). For example, in a study that explored women’s understandings and experiences of cervical cancer screening in the UK involving many participants who were from different ethnic and religious backgrounds, it was found that by emphasizing their status as an outsider and the

lack of knowledge they had about the participants' cultural and religious backgrounds, the researcher managed to elicit detailed accounts. In part, this was due to the empowerment of participants as "experts" vis-a-vis the researcher (Tinkler and Armstrong 2008). At the center of these questions lie the relations of power between researcher, researched, and research assistant, which will be discussed below. This goes to show the importance of reflecting on these threefold dynamics matters right from the beginning of any process of fieldwork planning.

Second, there are some practical questions relating to the research time frame and funding. Depending on the desired sample size and number of interviews, working with a research assistant can produce some time gains when researcher and research assistant conduct research activities separately and in parallel or when more than one research assistant can be employed. If the sample size is medium to large, given the available time, then sharing the workload with a research assistant may be an advantage. Likewise, if the researcher plans to conduct a high number of interviews in a given amount of time, then working with a research assistant can help reach the target. However, these benefits do not apply to cases where researcher and research assistant conduct research activities jointly, if translation is constantly needed for example, or where the research assistant leads the implementation of the research activity by herself/himself (Deane and Stevano 2016).

Another critical practical point has to do with funds available to remunerate the work of research assistants. As we discuss below, the relation with research assistants is first and foremost one of employment (Molony and Hammett 2007; Deane and Stevano 2016), therefore, the availability of adequate funds is necessary to employ a research assistant. The duration of employment as well as the tasks that the research assistant will be responsible for may well depend on the available funding. This is important both in the context of large research projects, where budgets need to cost research assistance appropriately, and in doctoral and other smaller research projects, where researchers are subject to tight financial constraints. Although these practical considerations are often neglected in the literature, they do shape the nature of research projects, their objectives, and the associated involvement of research assistants. To find out what is feasible with the available funds, it is advisable to investigate the ongoing hourly, daily, or monthly rates for research assistants in the context where research is to take place.

Third, there are issues that relate more specifically with the scope of each research project. A general guide on how to make a decision on whether a research assistant is needed is provided by the exercise of linking research questions to research methods. We break down the overarching research question into several sub-questions, and then we consider the best equipped method to address each research question (We both have Deborah Johnston to thank for this approach). For each research question and associated method, we reflect on the role a research assistant can play. What is the role of a research assistant if we plan to use participant observation to study intra-household decision-making among poor households? What is the role of the assistant if we plan to conduct interviews with farmers, NGO workers, or government officials? When participant observation is used in contexts where the researcher is not fluent in the participants' language, the presence of the research assistant is

necessary for the entire duration of the research activities. However, there are good reasons why, in some cases, it may be appropriate that research assistants lead the research activities. This may be due to the nature of the topics at hand, or with the respondents' ease to speak to the research assistant, rather than to the researcher, or better understand their accent. For example, during a qualitative study conducted in Tanzania on the relationship between population mobility and HIV risk (Deane et al. 2016), it was decided that in-depth interviews with participants that covered sensitive topics such as sexual behavior were to be led by the research assistants alone, in part to create a more conducive and safe environment for participants, as well to address the distorting presence that an observing lead researcher (who was not fluent in the local language), would have on the interview dynamic.

While there are no uniform answers to these questions, these are important issues that need to be carefully considered when planning field research. It is clear that the role of the research assistant is nested within broader historical and political processes underlying the nature of research, its time line, and the availability of research funding as well as the power asymmetries between researcher and participants. Researchers can follow key guiding questions to make decisions on whether they should work with one or more research assistants, but, crucially, they must consider how the practicalities do not transcend from the web of power relations operating at both the individual and the institutional level, which we discuss below.

3 Working with Research Assistants

3.1 An Employment Relation: Recruiting Research Assistants

As Molony and Hammett (2007) note, the relation between researcher and research assistant is shaped by a range of wealth and power asymmetries that are rooted in a broader set of international historical relations, but it is essentially one of employment. The researcher-employer needs to recruit a research assistant, establish a work relation, and manage it.

Once it is established that one or more research assistants are needed to carry out primary data collection, then researchers need to find suitable candidates for the job. For some researchers, it may be the first time they act as employers, therefore the process of finding research assistants, even more so in contexts that may be unfamiliar, should not be taken for granted. A number of practical routes can be taken. First, some attempts can be made prior to travelling to the research site. It may be useful to use research networks and connect with other researchers who have conducted research in the same settings as they may have contacts of research assistants they directly work with or have worked with in the past.

Second, it would be highly advisable to establish an affiliation with a local research institute. These collaborations are crucial not only as channels to find research assistants (Molony and Hammett 2007) but also to get to know the local research environment, meet other researchers, and eventually disseminate findings where they are closer to the realities they describe. Further, partnerships with local

research institutes are strongly encouraged by funding institutions, representing one positive, if often tokenistic, aspect of the current politics of research funding.

If collaborations with local research institutes are not possible and other attempts were unsuccessful, local university students may be willing to take up part-time jobs as research assistants. Students may be reached through teachers or announcements on the university campuses. Finally, it is also possible that the nature of research is such that the *best* research assistant is someone who is very familiar with the context, despite lacking connection with research, studies, or previous research assistance experience. This may be the situation of researchers working in remote areas, on sensitive topics, or in unsecure settings (Jenkins 2015). In these cases, building personal networks and using word of mouth may be the most effective ways to find suitable assistants.

In a formalized recruitment process, the researcher holds interviews and selects from a pool of candidates. What are the criteria to select a research assistant? The decision, as Molony and Hammett (2007), p. 295 suggest, entails considering a number of factors:

The selection of a research assistant is a key decision, where one must balance the academic qualifications with the experience and personality of the potential assistant in relation to the physical and social environment(s) in which the research is to be conducted.

Some have suggested that matching research assistants and research participants on a number of sociodemographic characteristics (Temple and Edwards 2002; Liamputtong 2010) is a viable selection technique. This would entail considering language, age, gender, education, socioeconomic status, and residence location. For example, the research assistant needs to be fluent in the language(s) spoken by research participants. However, it becomes immediately clear that the usefulness of the matching exercise is limited, unless it is complemented with a broader assessment of the triangular power relations between researcher, research assistant, and research participants (Deane and Stevano 2016). Consider a research project focused on women: It would seem appropriate to employ a woman as a research assistant. However, in many settings it is necessary to negotiate with male gatekeepers to gain access to women, which makes it possible that male research assistants may be better placed to navigate this process (Mandel 2003; Deane and Stevano 2016). Further, insights can be gained from research assistants themselves. In a reflective article in which Turner (2010) interviewed two former female research assistants on their experiences of the research process in Vietnam and China, both research assistants noted that they found men easier to interview than women, in part because the cross-gender dynamic created space for the development of strategies to deal with this, and also because within those contexts, it was more culturally acceptable for men to talk and share information, whilst women often deferred to their husbands and so interviews with them were often difficult. As Turner (2010), p. 212 notes, this is a surprising dynamic that contradicts perceived wisdom, as it is often assumed that “female assistants will be more comfortable interviewing females; likewise male assistants interviewing men.”

A related concern is the ethnicity of research assistants, and how this may influence the research process. Whilst it is common in cross-cultural settings to hire research assistants who have a similar cultural background to participants, often for linguistic reasons, this can blur the insider/outsider status of the researcher and influence the research process through the ways that research assistants have to mediate cultural norms, expectations, and structures. Ensuring that the influence that the ethnicity of the research assistant has on the research process is at least acknowledged, if not considered from the outset, is of vital importance. For example, in research conducted in the Mozambican province of Cabo Delgado (Stevano 2014), inhabited by three main ethnic groups – Macua, Maconde, and Mwani – the research assistant, a Maconde, was more of an insider with Maconde respondents and less so with Macua and Mwani interviewees.

A final dimension when trying to recruit the most suitable research assistant in cross-cultural qualitative research relates to the methodological expertise of the prospective research assistants. This can be a challenge in some settings, as due to the predominance of large-scale surveys as instruments for primary data collection, research assistants may have had prior experience of conducting structured interviews but not of more complex qualitative approaches, leading to difficulties in recruiting appropriately experienced research assistants (Molyneux et al. 2009). In this case, time must be taken to ensure that the prospective research assistant, especially if they have previously worked with questionnaire-based interviews, is informed and trained on the range of qualitative methods that will be used. The importance of recruiting research assistants who have experience and knowledge of qualitative methods is reflected in the influence that this may have on the research design itself. For example, in the Tanzanian study noted above, the research assistants' lack of experience with qualitative methods required a change in approach, with the planned life-history approach replaced with more straightforward semi-structured in-depth interviews. While this certainly influenced the research process, it highlights the ways in which researchers have to respond to the capabilities and experience of their research assistants during the fieldwork process.

Of course, it is entirely acceptable that the recruitment process is less formalized, especially when there is only one candidate, or time constraints are such that finding one suitable research assistant is preferred to selecting from a group. Nonetheless, even in informal recruitment processes, it is crucial to take into consideration power relations along the lines of gender, class, ethnicity, age, and so forth, as well as other requirements such as degree of insiderness, previous experience working as a research assistant, and commitment to the role. The absence of deterministic answers to these questions does not make them irrelevant. Reasoning on these issues requires weighing up the relative importance of each factor in the context of specific research projects, and this will lead to the best empirical choices under the given circumstances and constraints.

The labor relation highlights the responsibility of the *employer* to ensure that *employees* enjoy fair working conditions and conduct the research activities to the required academic and ethical standard. A central component of establishing a fair employment relation lies in clear contractual arrangements and adequate pay, issues

that are discussed in detail by Molony and Hammett (2007). Research assistants may be paid directly by the researcher or by the research institute through which they are employed. Depending on the payment channels used, the labor relation between research and research assistant will be more or less explicit (Deane and Stevano 2016). Either way, it is crucial that the employment offer is decent and provides very clear indication of tasks, payment structure, and duration of employment. An agreement on each of these issues should be sought prior to the beginning of the job. However, this financial relationship is not always easily managed, due to the existence of an often significant wealth asymmetry between researcher and research assistant (Molony and Hammett 2007), and also because the role that research assistants fulfil are multiple, overlapping, fluid and susceptible to change, and thus, not always easy to pre-define upfront. Further, as the relationship between researcher and research assistant develops due to the time spent together and the blurred boundary between employer and friend, the integration of the researcher into the personal network of the research assistant can lead to situations in which researchers are expected to help out financially in times of need beyond paying the agreed wage. And in some situations, research assistants, aware of the wealth asymmetries, may attempt to extract as much money as possible from the researcher (Molony and Hammett 2007). There are also other smaller financial issues to deal with, such as setting and managing expectations in terms of who pays for soda/tea or lunch during extended periods in the field. Managing these financial arrangements is thus not always an easy task, involving both obligational and philanthropic urges and the need to maintain the relationship as a contractual, business arrangement (Molony and Hammett 2007).

The duration of employment should reflect the time necessary for training, before the start of the research activities and also while data collection takes place. Training is critical to make sure that the research assistant can perform her/his role to the highest scientific and ethical standards (Liamputtong 2010). As noted above, there is some literature on training enumerators who conduct large-scale surveys. However, there is a gap in the literature on training of research assistants in qualitative social science research. Molyneux et al. (2009) make a strong case for placing training at the outset of the methodology in multi-method research. A number of activities can be carried out during the training sessions. It is necessary to explain the rationale and objectives of the research project as well as the scope of each research activity. What is the expected outcome of each research activity and what is the best way to obtain it? The research assistant can take up an active role in shaping the format and content of research activities, based on their knowledge of the context. This process can carry on for the entire duration of data collection as qualitative research is not subject to the fixity of questionnaires. Constant revision and adaptation of qualitative interviews is arguably one of the strengths of qualitative research, and the research assistant can play an important role in this process.

It has been argued that the employment relation between researcher and research assistant is multifaceted because the research assistant is also a friend and a companion (Turner 2010), on the one hand, and because there are other power asymmetries that mark the labor relation, on the other hand (Molony and Hammett

2007). Here, we draw attention on the risks that research assistants may be exposed to due to their position of insiders in relation to participants and their communities (As described by Cramer et al. (2016), we recognize that researchers are also exposed to risks when conducting primary research but, due to the objectives of this chapter, we focus on the risks potentially facing research assistants.). While research assistants are employees, they also guide the researcher through the process of data collection, facilitating interactions with authorities, building trust with participants and their communities, *de facto* leading the process through which researchers gain access to informants and, eventually, data. Thus, Jenkins (2015) notes, when the trust-building process is compromised – often due to factors that are beyond the control of research assistant and researcher, such as ethnic divides and any event that creates unjustified suspicion in the researched communities – assistants are exposed to risks. Cramer et al. (2016) reflect on a challenging episode when research assistants were detained by local security officials for having held interviews with farmworkers at their homes without permission from their employers, thus highlighting the risks of operating within networks of structures of power based. Researchers may lose access to research communities but research assistants, as people who live in the research context, may face risks that carry beyond the duration of the data collection process. Thus, it is the researcher's responsibility to try to anticipate and minimize a variety of risks that may emerge during the research process.

In sum, the recruitment of research assistants requires a degree of professionalism, transparency, and trust on the part of the researcher, who acts primarily as an employer. There are, however, a set of economic, political, and ethical issues we, as researchers, need to consider to establish a fair working relation with the research assistant. These include, quite obviously, adequate pay and working conditions, clear agreement on what the job entails, and high-quality training but also an open assessment of the potential risks and ways to minimize them.

3.2 Research Assistants' Tasks

Thus far, we have described the decision-making process researchers go through, from deciding if they need to work with a research assistant to employing one, but what will the research assistant eventually do? In this section, we discuss a set of tasks research assistants may be asked to perform before, during, and after fieldwork.

When funding allows it, it is advisable that the researcher arranges a scoping research trip to recruit an assistant and carry out the preliminary work to then run the research activities smoothly. Setting the scene includes establishing contacts with governmental and nongovernmental institutions and obtaining permission to carry out research, when needed. Research assistants may provide valuable contributions in the preliminary phases of fieldwork, by facilitating contacts with local institutions, authorities, and key informants. For example, in our recent fieldwork on food consumption among schoolchildren in Accra, Ghana, the research assistant managed the communication with the Accra Metro Education Office to obtain an updated list

of private and public schools and then permission to conduct interviews in a sample of schools. These networks of contacts and paperwork are a crucial step to ensure access to research participants and their communities. They also represent a first move toward building trust between the research assistant and the respondents, thus possibly making the subsequent research activities more welcomed.

To then consider the variety of tasks research assistants can perform during the implementation of research activities, it is useful to go back to the exercise of matching questions, methods, and role of research assistant described in an earlier section (How to assess when research assistants are needed). Depending on a number of factors, the research assistant may only translate, assist the researcher, colead interviews or take up full leadership, in either absence or presence of the researcher. Practically, the basic decision that needs to be taken is on who leads the activities. As mentioned above, there are different criteria that can be used. First, it depends on the research method used. For example, in focus groups or other collective interviews it may be useful that the researcher and the assistant perform different tasks, with one leading the interview and the other one taking notes. Second, the nature of the topic at hand matters. Sensitive topics may be handled better by local researchers. But, at the same time, it is worth considering the possible risks arising for the assistants, especially if they have a more visible leadership role. Third, considerations on the preference of respondents to speak to an insider or to an outsider may lead the researcher to decide that the research assistant leads the interviews, and vice versa. Different configurations have implications on the methods used, the ability to go “off-script” and follow up on interesting themes that emerge in the course of the interviews, and on the research flow, with simultaneous translation making activities longer and more tiring (Deane and Stevano 2016). For example, during a study in Bangladesh that aimed to investigate women’s experiences of emergency obstetric care, Pitchforth and van Teijlingen (2005) encountered challenges related to the flow of interviews when conducted with their research assistant as a translator. Not only did this make the interviews time consuming and disjointed due to the constant flow of information from researcher to research assistant to participant and back again, they also noted that the research assistant did not always interpret some questions or comments, or did not want to ask specific questions that seemed obvious to them. Reflecting on this issue, they came up with an alternative approach in which the research assistant led the interview and at key points during the interview summarized the conversation and gave the researcher the opportunity to input additional questions or lines of inquiry. This enabled the interviews to work more like a structured conversation and improved the flow but required the researcher to cede control of the interviews to the research assistant (Pitchforth and Van Teijlingen 2005). The cessation of control to research assistants was even more evident in the project conducted in Tanzania mentioned above. In this project, the researcher was not even present, and thus was completely reliant on the research assistants to ask the right questions and follow up on anything unexpected that arose (Deane and Stevano 2016). The exact configuration will have an impact of the depth of training and preparation required before research activities commence, as well as further muddying the already complex power dynamic between researcher and research assistant.

Importantly, research assistants participate in the on-going analysis of data collected. This can be done as regular informal conversations or more structured debriefs at the end of each research activity. More structured check-ups may be needed when research assistants lead the interviews (Molyneux et al. 2009; Deane and Stevano 2016). Different techniques have implications for the quantity and quality of data collected (Deane and Stevano 2016). For the purpose of planning, it is important to put time aside for the on-going data analyses. As much as it may look like a trivial observation, it is, on the contrary, meaningful in a scenario where conducting interviews tends to be given priority over reflecting on the material collected. It is time consuming to take notes on a regular basis and often what is not written will then be forgotten and lost later on.

Finally, in the post-fieldwork phase, the research assistant may still have a role to play. First, the researcher may decide to ask the assistant to read and comment on field reports, as an extension of the interim analyses described above. Second, joint publications can also be considered. This depends on the willingness of the research assistant to participate in writing up research. Research assistants who work for research institutes may have an interest in appearing as coauthors of research articles. However, researchers are also constrained by the boundaries of disciplinary practice. In some disciplines, such as medical science, nutrition sciences, and public health, researchers are expected to list as coauthors all people involved in the research process, including research assistants. Yet, other disciplines, such as economics, anthropology, development studies, normally include only the writing authors, and, additionally, researchers in these disciplines are encouraged to have solo-authored publications. It is more common in these disciplines to recognize the work of research assistants in the acknowledgements.

Research assistants' work is precious throughout field research. It is, therefore, important that researchers consider carefully how to manage the assistant's involvement, and acknowledge their contributions, not only to do justice to their work but also to reflect on the influence research assistants have on the shape of the research process and on the quality of the output.

4 Conceptual and Ethical Issues

By tracing the decision-making process researchers go through to recruit and work with assistants, it becomes evident that most practical decisions are intertwined with the web of power relations governing the interaction between researcher, research assistant, and participants. Previous work, especially by anthropologists and feminist scholars, has reflected on the positionality of researcher and researched and the need for a reflexive approach to research (Harding 1987; England 1994; Pack 2006; Ryan 2015; Suwankhong and Liamputtong 2015). Some have extended these reflections to include the research assistant as a third important actor (Temple and Edwards 2002). These approaches stress the subjective nature of these relations, thus focusing on the "values," "beliefs," "assumptions" that each actor – the researcher, the research assistant, the researched – bring in the research process, creating a "triple subjectivity"

(Temple and Edwards 2002, p. 11). As much as the inclusion of the research assistant in the picture is of paramount importance for thorough reflections on research methodology, the emphasis on subjectivities falls short of considering the materiality of these relations of power. We need to understand how the distribution of power along the lines of age, gender, nationality, class, race comes to shape the interactions between the people involved in the research process and how, in turn, research itself is shaped by them. And thus, we extend this analysis to include a consideration of the objective relations between researcher, research assistant, and participants that overlap with but are distinct from the triple subjectivities noted above (Deane and Stevano 2016).

The objective relations between research assistant and participant, and how these shape the research process and outcomes, are also important to consider. For instance, in the Tanzanian example, research assistants were frequently interviewing participants that were older, thus conferring a certain power dynamic, which was offset by other aspects, such as the fact that the research assistants were more educated. In other settings, it may be the ethnicity or the social class of research assistants vis-à-vis participants that matter. How these different dynamics play out in the research process is often difficult to disentangle, but they must be acknowledged. The relations between researcher and participant are also mediated by the research assistant, whether the researcher is present or not, and thus presents an extra layer of complexity when considering the role of research assistants. Whether these influences are addressed up front or reflected on during and after fieldwork activities, it is undeniable that they will impact the outcomes of the project.

Acknowledging that the researcher-research assistant relation is one of employment highlights fundamental material conditions of the relation, such as payment, contractual arrangements, and the responsibilities of both employer and employee. It also raises the issue of research ownership. For, as much as research assistants perform well at their job and contribute to the quality of research, the official ownership of research remains ultimately in the hands of the researcher-employer. This can have implications for how the research project is run, how and why some conflicts of interest arise, and may also help researchers understand the underlying dynamics of difficult relationships with research assistants – is your research assistant just being difficult because that is the way they are or because of these broader dynamics? As Molony and Hammett (2007) note, the relationship between researcher and research assistant brings into sharp focus the extractive nature of cross-cultural research, especially in low-income settings, and the unequal benefits that different parties derive from the process.

The question of ownership helps us see how the power dynamics we experience as researchers conducting fieldwork are nested in institutional relations, which set the boundaries within which we do research. Thus far, we have discussed the decisions, and the underlying power dynamics, we face as individual researchers. From this angle, the practice of silencing the research assistant is considered to be harmful because it does not acknowledge the invaluable work of assistants and their influence over the research process and output (Molony and Hammett 2007; Turner 2010; Caretta 2015; Deane and Stevano 2016; Jenkins 2015). As Jenkins (2015), p. 24 notes, “silencing the research assistant not only does a disservice to the extent of

their influence over our research – in both its positive and negative manifestations – but it also prevents an honest, open, and fundamentally important discussion of how we can collaborate with these figures in a more ethical manner.” However, the extent to which we can improve the ethical terms upon which we work with research assistants fundamentally depends on how research institutions and funding bodies govern the relations with partners in lower income countries.

Given the centrality of North-South research partnerships, especially in the fields of development and global health research (Bradley 2006; Murphy et al. 2015; Spiegel et al. 2015), it is essential to contextualize the experience of individual researchers within the broader picture. Although a discussion on the nature and implications of these partnerships is beyond the scope of this chapter, we want to underline the importance of the structural inequalities embedded in these collaborations in shaping the work relation between researcher and research assistant. As Bradley (2006), p. 15 notes, “this asymmetry [between northern and southern partners] manifests itself in the form of inequitable access to information, training, funding, conferences, publishing opportunities, and disproportionate influence of Northern partners in decision-making on the research agenda, project administration and budget management.” A more equitable engagement of research assistants is critically constrained by these asymmetries, in that ownership of research remains in the hands of the researcher, acting on behalf of their institution. Thus, there are ways, as described above, in which researchers can make the employment relation with their assistant fairer in terms of pay and working conditions. But, reflecting and writing about the role of research assistants does not resolve all ethical issues, many of which should rather be dealt with at the institutional level.

5 Conclusions and Future Directions

Researchers conducting qualitative social science research do not have much guidance on how to make decisions to find, recruit and work with research assistants. This chapter is important because it is an initial attempt to fulfil some of these gaps. Drawing on our own research as well as that of others, we have discussed a set of key practical considerations researchers need to address when planning their fieldwork – from assessing whether a research assistant is needed to managing a work relation with assistants. The intention of the exercise was not to provide uniform answers, but rather to identify key issues and reasoning to address them. While their impact on the overall research process will not always be known, an awareness of how research assistants can influence the quality of data collected, as well as the final analysis, will improve the data collection process.

It is evident that the practicalities of working with research assistants are entrenched with the power relations that shape interactions between researchers, research assistants, and participants. The central relation we discussed is that between the researcher and the research assistant, which leads to considering a set of key responsibilities and obligations the researcher has as the employer. Thus managing the relation with the assistant requires thinking about a series of practical

issues, such as adequate training, adequate pay, fair working conditions, and clear contractual arrangements. But, crucially, it is based on understanding the essential character of the relationship as one of employment. Researchers need to be more explicit in their acknowledgement of the work of research assistant and also need to reflect more on the influence they have on the research process and outcomes. However, there are important ethical concerns, stemming from the structurally unequal relations between partner institutions, that will not be resolved by individual researchers, or in the context of specific research projects.

Future contributions on this topic are much needed to fulfil a crucial gap in the literature on research methodology. Practical guidance for researchers would be significantly enriched if researchers doing cross-cultural research in the area of social science reflected, discussed, and wrote more on this topic. In particular, it would be useful to know more about different ways in which research assistants are employed by researchers and the type of assistance they provide in different contexts. At the same time, contributions exploring the institutional determinants of the habitual silence on the role of research assistant would be critical to help us see this issue within the bigger picture and reflect on what is needed to make the research landscape more conducive to fair collaborations between North and South institutions.

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Indigenous Statistics

97

Tahu Kukutai and Maggie Walter

Contents

1	Introduction	1692
2	Methodology	1693
2.1	What Is a Methodology	1693
2.2	Why Methodology Matters	1694
3	Exposing the Orthodoxy of Indigenous Statistics	1695
4	Indigenous Data Sovereignty	1696
5	Getting to Understand Indigenous Methodologies	1697
6	Indigenous Quantitative Methodology	1698
7	Indigenous Quantitative Methodology in Practice	1699
7.1	Case Study 1: Aotearoa NZ: Māori Concepts of Family	1699
7.2	Case Study 2: Australia: How Do Indigenous Children Grow Up Strong in Education	1702
8	Conclusion and Future Directions	1703
	References	1704

Abstract

Statistics about Indigenous peoples are a common feature of Anglo-colonizing nation states such as Canada, Australia, Aotearoa New Zealand, and the United States (CANZUS). The impetus for the production of most Indigenous statistics is the shared position of Indigenous disadvantage in health and socioeconomic status. In this chapter, we contrast statistics *about* Indigenous peoples with statistics *for* Indigenous people and statistics *by* Indigenous people. There are very significant differences between these categories of Indigenous statistics. At

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1691

the heart of these differences is the methodology that informs the research processes and practices. Statistics *about* Indigenous peoples often reflect the dominant social norms, values, and racial hierarchy of the society in which they are created. In the CANZUS states, these statistics are deficit focused and, at times, victim blaming. Also missing from these statistical portrayals is the culture, interests, perspectives, and alternative narratives of the Indigenous peoples that they purport to represent. We contrast these statistics with those from statistical research using processes and practices that are shaped by Indigenous methodologies. Indigenous methodologies are distinguished by their prioritization of Indigenous methods, protocols, values, and epistemologies. We conclude with two examples of what Indigenous quantitative methodologies look like in practice from Aotearoa NZ and Australia.

Keywords

Indigenous · Statistics · New Zealand · Australia · Colonization · Methodology

1 Introduction

The estimated number of Indigenous peoples ranges between 300 and 370 million, and comprises thousands of distinct polities covering all of the world's continents (Gracey and King 2009; Hall and Patrinos 2012). Statistics about Indigenous peoples (Given the diversity of Indigenous peoples, the United Nations does not have an official definition of "Indigenous" but rather invokes the following criteria: (1) Self-identification as indigenous peoples at the individual level and accepted by the community as their member; (2) Historical continuity with pre-colonial and/or pre-settler societies; (3) Strong link to territories and surrounding natural resources; (4) Distinct social, economic or political systems; (5) Distinct language, culture and beliefs; (6) Form non-dominant groups of society; (7) Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.) are a common feature of Anglo-colonizing nation states such as Canada, Australia, Aotearoa New Zealand, and the United States (the so-called CANZUS group; Meyer 2012). The impetus for the production of most of these Indigenous statistics is the shared position of socioeconomic and health disadvantage. In all of the four CANZUS nations, Indigenous peoples are far more likely to die younger, to experience much poorer health, to be unemployed, to be homeless, to be incarcerated, and to not have the same level of educational achievement as non-Indigenous citizens (Anderson et al. 2006; Cooke et al. 2007; Gracey and King 2009; Anderson et al. 2016; see also ► Chaps. 87, "Kaupapa Māori Health Research," and ► 88, "Culturally Safe Research with Vulnerable Populations (Māori)").

In this chapter, we not only discuss statistics *about* Indigenous peoples but also statistics *for* Indigenous people and statistics *by* Indigenous people. There are very significant differences between these categories of Indigenous statistics. At the heart of these differences is the methodology that informs the research processes and practices. Methodology matters and we demonstrate how the methodology

informing the standard trope of statistics about Indigenous people in the CANZUS states are deficit focused and, at times, victim blaming. We contrast these statistics with those from statistical research using processes and practices shaped by Indigenous methodologies.

2 Methodology

2.1 What Is a Methodology

The terms “method” and “methodology” tend to be used interchangeably within the health and social science research literature. However, they mean quite different things. While both are related to the practice of doing research, they differ conceptually. Researchers need to have both a methodology and a method for the conduct of good research. All kinds of research, not just research related to Indigenous peoples, have a methodology (see also ► [Chaps. 6, “Ontology and Epistemology,”](#) ► [87, Kaupapa Māori Health Research,”](#) and ► [90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze”](#)).

The term “method” has a straightforward meaning. It refers to the method of collecting and/or analyzing data. For a qualitative research project exploring how Aboriginal women experience breast cancer treatments, the method might be in-depth interviews. For a research project exploring heart disease rates among urban Māori, the method would be statistical analysis. Despite what is written in some texts, methodology is not primarily related to whether the research has a qualitative or a quantitative base.

So what is a methodology? Basically, it is the framework that guides how the researcher approaches the research. This framework is not always consciously understood by researchers, especially those from dominant social, cultural, and racial groups. As has been argued elsewhere (Walter 2010; Walter and Andersen 2013), the basis of this guiding framework is the social positioning of the researcher. Social positioning relates to the race, class, gender, and social and cultural space that the researcher/s occupy. With different social positioning attributes comes different sets of values and belief systems (axiological elements) that can, for example, help determine what research questions the researcher thinks are important. The social position of the researcher will also be important in shaping what data or knowledge sets will be gathered (epistemological elements) and, if there is more than one set of knowledge, which knowledge set is prioritized. Social positioning also influences how researchers see the world, their place in it, and the place of others who are not like themselves (ontological elements).

Methodology can also affect the choice of method. This is because it is important for a method to be able to gather the sort of data that the researcher needs to address the research questions. Sometimes this means developing new research methods. For example, Yarning is an Aboriginal research method built around Aboriginal ways of communication (see also ► [Chap. 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze”](#)). But Yarning is more than just Aboriginal people talking. As argued by Bessarab and Ng’andu (2010), Yarning as a research method

is also a process of meaning making and communicating in culturally appropriate ways. It is, therefore, likely to be much better method fit for researchers working with Aboriginal people than the traditional (Western) method of in-depth interviewing.

2.2 Why Methodology Matters

Methodology matters to the way research is done and to the findings that result. Quality research should always make obvious the methodology that informed the research process. When the research relates to Indigenous populations or cultural minorities, a clear articulation of the research methodology is even more crucial. This is because while Indigenous peoples are the frequent objects of health and social science research, they are far less likely to be the commissioners, research designers, or data interpreters of that research. In all CANZUS countries, the vast majority of Indigenous-related research is still undertaken by non-Indigenous researchers and commissioned by non-Indigenous policy makers (Taylor 2008; Kukutai and Walter 2015).

The imbalance is important because the social position of the subject “knower” (e.g., policy analyst within government) and the social position of the object of statistical study (Aboriginal and Torres Strait Islander and Māori people) are not even remotely the same. If these differences are reflected in the values that inform the research, the prioritization of knowledge, the analysis, and the interpretation of results, then the outcome is likely to focus on Indigenous “deficits” (Valencia 2012). Deficit research focuses on Indigenous problems and locates the source of those problems within Indigenous populations and culture. The validity of this approach and its methodological underpinnings has long been challenged by Indigenous scholars (see Tuhiwai Smith 1999) but still remains a dominant trope in Indigenous data (see next section).

To demonstrate how methodology operates in practice, let’s relook at our research examples. In the qualitative example of exploring the experience of breast cancer treatment of Aboriginal women, there are some key methodological questions. More critically, differing answers to these questions will produce very different research projects and different findings. For example, do the researchers decide that the data are only going to be from Aboriginal women? Or will treatment personnel be included? If so, what will happen if the report from the treatment personnel and Aboriginal women differ? Whose perspective will be deemed more accurate? Will and how will the research process and practice be adjusted from mainstream models to capture the specific experiences of Aboriginal women? And which women? Are we talking about urban or remote experiences or both? Aggregation of “the” Aboriginal population into one category is a common practice in Australian research. This practice, however, ignores the reality of over 500 Aboriginal nations in Australia, all whom have different cultural, historical, and contemporary realities.

For our second example, cardiovascular disease (CVD), the statistical data already exists. However, the researcher’s methodology will still shape the research outcomes. In Aotearoa NZ, ischemic heart disease accounts for over half of all cardiovascular disease mortality and the age-standardized ischemic heart disease

mortality rate among Māori (35+ years) is more than twice as high as that among non-Māori (RR 2.14, CI 2.02–2.27) (Age standardized rates can be accessed at: <http://www.health.govt.nz/our-work/populations/Māori-health/tatau-kahukura-Māori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/cardiovascular-disease>). What factors might explain why Māori have higher rates of heart disease at younger ages? Researchers without a strong understanding of Māori culture, values, and life circumstances might line up the usual suspects of heart disease: smoking, diet, and exercise. Their choice of such variables may be influenced by negative stereotypes of Māori people that circulate in the public discourse and which define the “problem” of Māori CVD as primarily one of poor individual choices and health behaviors. Subsequent policy interventions may also be focused on promoting individual lifestyle changes. This is despite the substantial evidence that such an approach has a limited effect in disadvantaged populations because of the failure to address the issues that gave rise to the behaviors.

By contrast, a Māori researcher who is embedded in both their discipline and their culture will likely include elements of the social determinants of health, which are the underlying economic and social conditions that drive racial health inequities (Commission on Social Determinants of Health 2008). These factors are inclusive of the heavy socioeconomic disadvantage experienced by Māori related to dispossession, colonialism, and ongoing marginalization including institutional racism and unmet needs in access to high quality and culturally appropriate healthcare services (Ajwani et al. 2003; Kerr et al. 2010; Axelsson et al. 2016). Focusing on these distal determinants of health, and how they shape the distribution of more immediate risk factors such as poor diet and ultimately CVD, engenders a different understanding of health inequities and approaches to reducing them. Policy responses might include engaging Māori in the design and delivery of culturally grounded health services, addressing the institutional barriers to timely diagnosis and treatment pathways, and taking a broader whānau (family) approach to health promotion rather than a narrow individualistic focus (Durie 2003; Kerr et al. 2010; see also ► Chaps. 87, “Kaupapa Māori Health Research,” and ► 88, “Culturally Safe Research with Vulnerable Populations (Māori)”).

The question then arises, if methodology is so important to the research process, why is it so frequently not articulated within research? The answer seems to be that researchers whose social positioning places them in the dominant racial or cultural group have not been trained to recognize that their social positioning directly affects how they “do” research. In cross-cultural research, such a lack of researcher reflexivity is a recipe for at best, poor quality research, and at worst, research that does harm to the group it is professing to research.

3 Exposing the Orthodoxy of Indigenous Statistics

In cross-cultural health and social science research, the traditional way of doing Indigenous research flows from the dominant model of what Indigenous statistics looks like within Aotearoa New Zealand, Australia and other first-world colonized

nations. The privileging of mainstream “mental models” to frame and explain Indigenous peoples has real-life consequences for Indigenous peoples.

Indigenous researchers and communities have made numerous criticisms of how statistical agencies collect, disseminate, and analyze Indigenous data. The criticisms include a tendency to focus on Indigenous “problems” rather than strengths; a failure to recognize Indigenous culture, values, and practices in the measures and processes used to gather and analyze data; a failure to prioritize Indigenous needs in data system development; ineffective measures to address longstanding data quality issues such as Indigenous undercounting; and a tendency to use token consultation rather than meaningful Indigenous engagement and partnership (Taylor 2009; Robson and Reid 2001; Prout 2012). In response to these problems, Kukutai and Walter (2015) proposed five development principles aimed at enhancing the functionality of official statistics for both Indigenous peoples and national statistics agencies.

These concerns are not limited to domestic policy making. Global forums, such as the United Nations Permanent Forum on Indigenous Issues and the Special Rapporteur on the Rights of Indigenous Peoples, have stressed the importance of high quality and meaningful data for enabling Indigenous development. However, the extent to which governments recognize the existence of Indigenous peoples in official statistics varies widely. Preliminary findings from the *Ethnicity Counts?* project show that, of the 150 countries and territories that encompass Indigenous peoples, only 45% identify Indigenous peoples in the population census (Taylor and Kukutai 2015). In some countries, there are multiple questions relating to Indigenous identity. In Aotearoa NZ, for example, Māori can be identified by ethnicity, ancestry, tribal affiliation, and language. However, in the majority of countries, Indigenous peoples are statistically invisible. Ironically, some of these countries, such as Sweden and Norway, have some of the most well-developed official statistics systems in the world.

The census is the flagship of official statistics in many countries. It provides the population-level denominator for many indicators of well-being within countries, as well as for many of the UN’s Sustainable Development Goal indicators (United Nations General Assembly 2015). The extent of Indigenous invisibility in the census has far-reaching implications for the ability to monitor Indigenous development on a global scale. The 2015 State of the World’s Indigenous Peoples report noted that it is still often difficult to obtain a global assessment of Indigenous peoples’ health status because of the lack of data (United Nations Department of Economic and Social Affairs 2015).

4 Indigenous Data Sovereignty

One of the questions raised by Indigenous quantitative methodologies is who has the power to control Indigenous data. In the CANZUS states, there has been a growing call for greater control over the collection, dissemination, analysis, and storage of Indigenous data. This call for “Indigenous data sovereignty” (Kukutai and Taylor 2016) is founded on Indigenous rights to self-determination which emanate from their inalienable relationships to lands, waters, and the natural world, and which are encapsulated in Articles 3 and 4 on the United Nations Declaration on the Rights of

Indigenous Peoples (The full text of the UNDRIP can accessed at: http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf). The idea of data sovereignty is a recent development of the digital age referring to the management of information in a way that is consistent with laws, practices, and customs of the nation-states where data are located. Indigenous data sovereignty sees Indigenous data as subject to the laws of the nation from which it is collected and requires a relocation of authority over relevant information from nation states back to Indigenous peoples (Snipp 2016). Indigenous data is broadly understood as data about Indigenous peoples, their territories, conditions (including health conditions), and ways of life. Such data includes genetic samples, linked “mega” datasets, digitized health records, and data on land and other natural resources. In the context of cross-cultural research, the implications of Indigenous data sovereignty are far reaching because it has the potential to transform power relationships in terms of who owns, governs, and controls access to and management of Indigenous data.

In the CANZUS states, Indigenous peoples are giving practical expression to various forms of Indigenous data sovereignty. In Canada, there are the First Nations’ principles and practices of ownership, control, access, and possession over First Nations data known as OCAP[®] (First Nations Information Governance Centre 2014). OCAP[®] was created by the First Nations Information Governance Centre to help guide the development of the First Nations Regional Health Survey (FNRHS), the only First Nations-governed, national health survey in Canada that collects information about First Nation on-reserve and northern communities. The development of OCAP[®] was motivated by negative experiences with research projects conducted by non-First Nations people that did not benefit First Nations people or communities. OCAP[®] ensures that First Nations own their information and respects the fact that they are stewards of their information, much in the same way that they are stewards over their own lands. It also reflects First Nation commitments to use and share information in a way that maximizes the benefit to a community, while minimizing harm. First Nation communities have passed their own privacy laws, established research review committees, entered data-sharing agreements, and set standards to ensure OCAP[®] compliance. Other Indigenous data sovereignty initiatives are being driven by Te Mana Raraunga, the Māori Data Sovereignty network in Aotearoa NZ, the US Indigenous Data Sovereignty Network, and the Yawuru Native Title holders of Broome in Western Australia (Yap and Yu 2016). Collectively, these networks and organizations, and others like them, are developing new ways of “doing” Indigenous data that are challenging conventional methods and methodologies.

5 Getting to Understand Indigenous Methodologies

The deficiencies of traditional Western research methodologies for Indigenous peoples have led Indigenous scholars, globally, to develop Indigenous methodologies. Indigenous methodologies are a paradigm rather than a category of methodologies. Each, however, shares a philosophical base. This base is concisely summed up by Sami scholar Porsanger (2004) when she states that Indigenous methodologies all

reflect Indigenous ways of knowing, doing, and being. In doing so, they make visible what is meaningful and logical for Indigenous people and Indigenous understandings of the world.

The field of Indigenous methodology scholarship was led by the ground-breaking work of Linda Tuhiwai Smith (1999). Smith's book, *Decolonizing Methodology: Research and Indigenous Peoples*, details the tenets of Kaupapa Māori, a methodology intricately connected to Māori philosophy and principles, the validity and legitimacy of Māori, Māori language (Te Reo Māori) and culture, and Māori autonomy over their own cultural well-being. Moewaka Barnes (2000) emphasizes three defining principles of this approach:

- It is by Māori for Māori.
- Māori worldviews are the normative frame
- Research is for the benefit of Māori.

In a similar vein, Native Hawaiian scholar Ku Kukahala, the first person to earn a PhD in Indigenous education, highlights the importance of Hawaiian cultural protocols in her integration of existing heuristic methodology and Indigenous epistemology (2004). In Australia, Aboriginal scholar Karen Martin (2003, 2008), aligns the philosophical underpinnings of Indigenous methodology into theoretical principles. These require a recognition of Aboriginal worldviews, knowledge, and realities; the honoring of Aboriginal social mores; the social, historical, and political contexts which shape Aboriginal experience, lives, positions, and futures; and the privileging of the voices, experiences, and lives of Aboriginal people and Aboriginal lands. Native American scholar Margaret Kovach (2009) focuses on qualitative research practices in her theorizing of Indigenous methodologies. She argues that Indigenous methodologies are distinctive from Western and other methodological frames, and are distinguished by their prioritization of Indigenous methods, protocols, meaning making, and epistemologies in how to undertake research processes and research practice.

Indigenous methodology scholarship is also emerging from non-Anglo colonized nation states. Botswanan scholar Bagele Chilisa (2011) for, example, uses a post-colonial frame to demonstrate how methodologies are not restricted to academic knowledge systems. Her Indigenous methodological stance focuses on how the paradigms and practices of research can support Indigenous epistemologies and honor integrative knowledge systems (see also ► Chap. 15, “Indigenist and Decolonizing Research Methodology”).

6 Indigenous Quantitative Methodology

It is fair to say that, within the diverse spectrum of Indigenous methodologies, there is a strong preference toward qualitative methods and a widely held view that statistical research sits in tension with “Indigenous ways of knowing” (Kovach 2009). This is largely due to the perception that quantitative research methodologies are rooted in a Western *positivist* tradition that relies on “external evidence, testing

and universal laws of generalizability...contradict[s] a more integrated, holistic and contextualized Indigenous approach to knowledge” (Kovach 2009, p. 78). The question then arises – what does a quantitative methodology built on Indigenous ways of knowing look like?

In their book *Indigenous Statistics*, Tasmanian Aboriginal scholar Maggie Walter and Metis scholar Chris Andersen (2013) tackle this question directly, proposing a way to move the understanding of Indigenous methodologies into the field of quantitative research. Dominant ways of doing Indigenous statistics, they argue, shortchange Indigenous peoples and communities through their narrow portrayal of who Indigenous peoples are, and their circumscription of how Indigenous people can be understood. Mainstream narratives of Aboriginal and other Indigenous populations in Anglo-colonizing nation states are based on data about Indigenous peoples that the nation state, rather than Indigenous peoples, deem to be important. The result is a depressing familiar role call that Walter (2016) calls 5D data: data about Indigenous people that focuses on disparity, deprivation, disadvantage, dysfunction, and difference.

The central problem of Indigenous statistics is that population or racial group statistics are not neutral data. Rather, they reflect the dominant social norms, values, and racial hierarchy of the society in which they are created. In Australia and Aotearoa NZ, these dominant social norms and values typically reflect those of Anglo/European settler descendants. Norms can be thought of as the shared expectations for social behavior around what is culturally desirable or acceptable. Norms are evident in everyday interactions, in institutions such as schools and healthcare services, and in policy approaches. The power of these norms comes from their “taken for granted nature” – very rarely are they made explicit or visible like formal rules. Statistics, and especially official statistics, embody norms but hold an aura of objectivity and tend to be presented and understood as “facts.” The trouble is that these “facts” only tell a very small, and specifically framed, part of the reality of Indigenous peoples. What is not present in these statistical portrayals is the culture, interests, perspectives, and alternative narratives of the Indigenous peoples that they purport to represent.

Indigenous quantitative methodologies, in contrast, can support the development of statistical portrayals that go beyond the narrow, frequently pejorative, reflections that dominate official statistics of Indigenous peoples. Moreover, Indigenous statistics developed from an Indigenous methodological frame can, as argued by Walter and Andersen (2013, p. 73) “speak back” to the state in a way that both incorporates Indigenous knowledge and is ontologically translatable to state actors. We illustrate this by way of our two case studies below.

7 Indigenous Quantitative Methodology in Practice

7.1 Case Study 1: Aotearoa NZ: Māori Concepts of Family

In this section, we discuss two examples of what Indigenous quantitative methodologies look like in practice from Aotearoa NZ and Australia. The first case study is from a project exploring Māori expressions of whānau or family (Kukutai et al.

2016). Families are a fundamental social unit in all societies but vary greatly in terms of their form, function, and meaning. Families are also an important focus for research, public policy, and service delivery, from the immunization of children, to state-funded assistance for single parents, and elder care. In Aotearoa NZ, statistical studies of Māori families have tended to focus on household structure and circumstances and, more recently, on vulnerable children and family violence (Vulnerable Children Act 2014). These portrayals are often deficit focused and viewed through the lens of Western theoretical models. Missing from these statistical narratives are Māori perceptions of who their whānau are, how their whānau are doing, and what whānau well-being entails (Cunningham et al. 2005; Tibble and Ussher 2012).

The whānau concept and well-being project is a collaboration between all-Māori research team and government policy agencies (We thank our colleagues at the Social Policy Evaluation and Research Unit (Superu), Te Puni Kōkiri, the Ministry of Māori Development, and the Superu Whānau Reference Group.). Much of the analysis is drawn from “Te Kupenga,” a nationally representative postcensal survey of well-being among Māori adults, which was conducted for the first time in 2013 (Kukutai et al. 2016). Unlike other official surveys such as the Census and General Social Survey, Te Kupenga was specifically designed with Māori values and priorities in mind and had substantial input from Māori researchers, communities, and policy makers (Statistics New Zealand 2009). The initial stage of the project focused on two key questions:

1. How do Māori define who belongs to their whānau?
2. How are expressions of whānau related to factors such as cultural identity, household living arrangements, and social context?

The word whānau literally means to “to be born” or to “give life.” While there is no univocal definition of whānau, there is a broad consensus that genealogical relationships form the basis of whānau, and that these relationships are intergenerational, shaped by context, and given meaning through roles and responsibilities (Lawson-Te Aho 2010). From a Māori standpoint, to be part of a whānau is to share common “whakapapa.” In a traditional sense, whakapapa is understood as descent-based relationships which extend from the physical world to the spiritual world (Kruger et al. 2004). Whakapapa also refers to the layers of relationships that connect individuals to ancestors, to the living, and to the natural environment (Te Rito 2007). Whakapapa relationships are not just ways of situating individuals within a kin group but are connected to roles, responsibilities, and obligations including mutual acts of giving and receiving, and the intergenerational transmission of knowledge.

The literature also refers to the concept of kaupapa whānau which is based on a common purpose or shared interests (Lawson-Te Aho 2010). In kaupapa whānau, “family-like” relationships of support and reciprocity are established as individuals purposefully engage to achieve a common goal. An oft-cited example is that of Māori language revitalization and preschool Māori language nests called kōhanga reo (Smith 1995). This expansive understanding of family is far removed from Euro

normative concepts of family, especially those emphasizing the household as the economic unit of production. But, how do these culturally grounded understandings of whānau play out in the context of a representative national survey?

In defining whānau, the approach taken in Te Kupenga was to acknowledge kinship and interest-based whānau and leave it to the individual to define their own whānau within four broad relationship categories (Tibbles and Ussher 2012). The question and response categories are shown in Fig. 1. Respondents could select as many categories as they needed. For the statistical analysis they were grouped into one of four mutually exclusive categories describing the broadest concept of whānau category reported, ranging from nuclear family to friends and others. The distribution can be seen in Table 1.

Just over 40% of respondents in Te Kupenga reported that their whānau *only* comprised immediate relatives, that is, parents, partner/spouse, brothers, sisters, brother, sister, parent in-laws, and children. A further 15% reported that their whānau included grandparents and grandchildren, and about one-third included extended whānau such as aunts, uncles, and cousins. Interestingly, nearly 13% of Māori counted close friends and others as part of their whānau.

Regression analyses showed that household-based living arrangement – the conventional way of measuring family in Aotearoa NZ – is a very poor predictor of how Māori see their whānau. More important are demographic factors (age, region) and cultural factors including connectedness to customary communities, access to cultural support, and having a high regard for Māori culture. Māori with

Describe whānau (qWHAWhanauDescribe)

Which group or groups include those you were thinking about as your whānau? You can select as many as you need.

A parents, partner/spouse, brothers and sisters, brothers/sisters/parents in-law, children	C aunts and uncles, cousins, nephews and nieces, other in-laws
B My grandparents , my grandchildren	D close friends, others

Fig. 1 Whānau question from Te Kupenga 2013

Table 1 Broadest concept of whānau (family) reported by Māori respondents in Te Kupenga 2013

	Per cent
A. Parents, partner/spouse, brothers and sisters, brothers/sisters/ parents-in-law, children	40.2
B. Grandparents/grandchildren	15.2
C. Aunts, uncles, cousins, nephews, nieces, other in-laws	31.9
D. Close friends/others	12.5

strong cultural connections tend to have a broader concept of whānau. The analysis has also helped to clarify the contexts within which nongenealogical relationships are perceived as being “whānau-like.” Interestingly, those who have participated in Māori language education and lived in homes where Māori is spoken are more likely to include friends and others as part of their whānau. Similarly, Māori who provide support to people living in other households, and those in challenging economic circumstances, are also more likely to count nonrelatives as part of their whānau. The project has important implications for research and policy focused on families. It suggests that, for Māori, household-based measures of family are a very poor proxy for the more complex set of whānau relationships that exist and that policy responses based on these narrow Western concepts may have limited relevance.

7.2 Case Study 2: Australia: How Do Indigenous Children Grow Up Strong in Education

The following case study demonstrates practically that it is not the method, in this case statistical analysis, but the methodological frame that shapes research. A key element is that the focus is not describing or investigating “the problem” of lower educational achievement for Aboriginal and Torres Strait Islander children as is the traditional research approach. Rather, the focus is on identifying the causes and the best ways to achieve good educational outcomes.

The all Aboriginal research team are researching Aboriginal and Torres Strait children’s (0–18 years) lived experience of schooling and education. The study’s objectives are to:

1. Identify the critical intersections of events that impact on Indigenous children’s educational chances across the childhood life course across locations.
2. Identify the pathways, protective factors, and resilience dimensions that support educational achievement for Indigenous children irrespective of disadvantage.

The project uses data from the Longitudinal Study of Indigenous Children (LSIC) a national longitudinal panel study conducting annual waves of data collection, with Wave 1 (2008) surveying families of 1,670 Indigenous children from 11 sites across Australia. Face-to-face interviews are conducted between the study child’s primary parent and locally employed Indigenous research administration officers. Use of the LSIC data is a key part of the research project’s methodological frame. The study is guided by an Indigenous-led Steering Committee and its question topics, question design and conduct and are overtly shaped by Aboriginal and Torres Strait Islander perspectives and values.

The starting premise of this *Strong in Education* research project is that while a lot is known about Indigenous children, it is a certain sort of knowledge from a particular perspective. Government statistics tell us that Aboriginal and Torres Strait Islander children are much more likely to live in poor households and do far less well in the education system than non-Indigenous children. They also consistently record

that Aboriginal and Torres Strait Island children are more likely to miss school, be suspended, and less likely to go on to higher education. What such existing statistics do not do is tell us what factors support good education and resilience for Aboriginal and Torres Strait Islander children. Identifying those factors is the key aim of this research. Within this, epistemologically, the analysis centers Indigenous people's knowledge, concepts, and worldviews.

The research's key concepts also reflect an Aboriginal and Torres Strait Islander methodological frame. The term "Strong" is conceptualized as the deployment of resilience to achieve good education despite adverse life circumstances. "Good education" refers to academic achievement to non-Indigenous median norms but also to cultural and community education (Malin and Maidment 2003; Andersen and Walter 2010). "Resilience" refers to the ability to cope with stress and adversity and do well in life despite difficulties (Gunnestad 2006). Its conceptualization within the research recognizes the interface of Indigenous social and cultural resilience with individual/family resilience and that social, cultural, and identity practices that support positive adaptation are integrally connected to resilience (Lalonde 2006).

Recent results from examinations of LSIC data in relation to educational outcomes find that parental and child social and emotional well-being are strong predictive factors for children's reading scores (Anderson et al. *in press*) and that how well the primary parent thought their child's school understands the needs of Indigenous families was a consistent predictor in how involved parents were with their child's schooling (Trudgett et al. *in press*).

8 Conclusion and Future Directions

In the CANZUS states, governments continue to invest substantial time and resources in monitoring the well-being outcomes of Indigenous peoples. In recent decades, governments in these countries have amassed a wealth of statistical data on Indigenous populations, all of whom are a significant focus of population research and policy in their respective countries. However, the categories and contexts employed in statistics about Indigenous peoples typically reflect dominant group norms, and their social and economic institutions. Because statistics about Indigenous peoples rarely encompass Indigenous methodologies, key aspects of Indigenous life are either missing or misrepresented. These epistemological and methodological shortcomings have stimulated calls for approaches for statistics that are *by* and *for* Indigenous peoples, rather than simply *about* them. In this chapter, we have identified key differences between these statistical approaches and the crucial importance of methodology for determining which questions are asked, and which processes and practices are employed.

In terms of future directions, major data transformations will raise new challenges along with potential opportunities. Technological innovations in the private sector involving big data are changing how data are used, most evident in the area of health. In the United States, genomics and big data science are being exploited in new ways to provide targeted, predictive, and personalized care in a "precision health"

approach. Official data practices are also being transformed as governments seek alternatives to traditional data collection practices. Aotearoa NZ is at the forefront of these changes with several major initiatives that will fundamentally alter the national data ecosystem. These include legislative reform to enable greater data sharing across agencies (NZ Government 2014), a greater emphasis on extracting social and economic value from data, and the use of linked data on individuals and families to inform the government's social investment spending through targeted inventions (The Treasury 2016). Given that Māori are disproportionately the subject of government interventions, these shifts raise a number of key issues about Māori data governance, ownership, and access. The rise of linked mega datasets and broader data sharing is likely to become a standard feature of official statistics in all of the CANZSUS states in the near future. The capacity of Indigenous peoples to benefit from the "data revolution" will likely depend on the extent to which they are able to exert meaningful influence and oversight of the practices, processes, and principles that emerge over the next decade.

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A Culturally Competent Approach to Suicide Research with Aboriginal and Torres Strait Islander Peoples

98

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Contents

1	Introduction	1708
2	Understanding Suicide in Aboriginal Communities	1709
3	Awareness of the Historical Research Context	1711
4	Understanding and Applying Ethical Research Principles	1712
5	Cultural Competency Throughout the Stages of the Research Journey	1713
5.1	Developing Relationships	1713
5.2	Deciding on a Research Topic	1716
5.3	Applying an Appropriate Research Methodology	1716
5.4	Seeking Ethical Approval	1717
5.5	Engaging with Research Participants	1718
5.6	Reporting and Disseminating Findings	1718
6	Conclusion and Future Directions	1719
	References	1719

Abstract

Despite the strength and resilience of Aboriginal peoples, suicide has profound and ongoing impacts for individuals, families, and communities, and has been identified as an area requiring further research. This chapter outlines a culturally competent approach for conducting social and emotional well-being research, from the perspective of non-Aboriginal researchers. The chapter begins by outlining the topic of suicide in the context of Aboriginal peoples and history, as a base from which to understand approaches to researching this complex topic.

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1707

Sensitivities associated with conducting research as non-Aboriginal researchers are outlined, stressing the importance of developing a consciousness toward the historical relationship between Aboriginal and non-Aboriginal Australians. The chapter then introduces important ethical principles, which can be used to guide culturally competent practice throughout the research journey. Specific methodological approaches are outlined, with an emphasis on those that are participatory in nature. Although the topic of suicide is utilized as a backdrop in this chapter, the approaches discussed here are transferrable to research exploring a range of social and emotional well-being concerns experienced by Aboriginal communities.

Keywords

Social and emotional well-being · Collaboration · Participatory research · Strengths-based research · Suicide · Aboriginal people

1 Introduction

Despite their resilience, strength, and ongoing connection to culture, Aboriginal peoples experience profound inequities across a spectrum of social and emotional well-being concerns. In particular, suicide, which is recognized as a global public health priority (WHO 2014), has been identified as an area in critical need of research among Aboriginal communities (King and Brown 2015). In light of a history of poor research practices and experiences, research with Aboriginal people needs to be carried out in a culturally competent manner. Cultural competency has been argued to be a vital strategy for reducing inequalities in health experienced by Aboriginal people (Bainbridge et al. 2015; see also ► Chaps. 88, “Culturally Safe Research with Vulnerable Populations (Māori),” and ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research”).

Although the importance of culturally competent practice is widely recognized in the context of health care, its application to health research appears to have received less attention. This is surprising, given that cultural competency is essential to all stages of the research process, including building and maintaining relationships, designing and implementing methodological and data collection approaches, analyzing and interpreting results, and disseminating findings. Papadopoulos and Lees (2002) have proposed a four-concept model for cultural competency, adapted from their work in health care. This includes: cultural awareness – whereby researchers reflect on, understand, and challenge their own values, perceptions, behavior, and presence, and how these relate to the research process; cultural knowledge – which involves engaging with diverse cultural groups and disciplines to understand similarities, differences, and inequities in health, and how these might be socially determined; cultural sensitivity – through partnering with research participants, and building trust, respect, and empathy throughout the research; and cultural competency itself – which is demonstrated through synthesis and application of awareness, knowledge, and sensitivity, and involves a commitment to engaging participants, organizations, and communities in all stages of the research. Working toward cultural competency is an

ongoing process and is considered vital as it can “lead to high quality, valid research irrespective of research design which can be used to inform the delivery of relevant health-care to all members of society” (Papadopoulos and Lees 2002, p. 263).

This chapter draws on our commitment and ongoing learning toward cultural competency as non-Aboriginal researchers, with experience and interest in mental health and suicide prevention, particularly among diverse, vulnerable, or marginalized communities. Our combined experiences in the specific area of suicide research with Aboriginal peoples include: literature reviews exploring the issue of suicide among Aboriginal young people and adults; as well as being part of a team of researchers and clinicians who engaged with the Aboriginal health sector in a project which involved the development, delivery, and evaluation of a community-wide suicide prevention training program throughout regional South Australia. The learning presented in this chapter has been greatly assisted by the time, wisdom, sharing, and expertise of our Aboriginal colleagues, to whom we would like to express our sincere thanks (see also ► Chap. 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze”).

We would also like to acknowledge the diversity of the Aboriginal people of Australia and recognize that it is preferable to refer to specific language and/or cultural group names where possible. Given the broad nature of this chapter, the term “Aboriginal” will be used throughout to collectively refer to Aboriginal and Torres Strait Islander peoples, in line with recommendations suggested by Australia’s National Aboriginal Community Controlled Health Organization (NACCHO 2016).

2 Understanding Suicide in Aboriginal Communities

Developing an ongoing awareness of suicide and its impacts for Aboriginal communities is an important precursor to undertaking research in this area. Despite being considered a rare occurrence prior to the 1970s, rates of suicide have “increased dramatically over the last three decades from levels that were previously much lower than the wider Australian population” (Hunter 2007, p. 89). The most recent statistics show that suicide rates were twice as high compared to rates for non-Aboriginal Australians in 2015 (ABS 2016). Between 2011 and 2015, suicide was the leading cause of death for Aboriginal people aged 15–34 years, and the second leading cause of death for those aged 35–44 years (ABS 2016). Overall suicide rates are particularly concerning among certain age groups. For example, Aboriginal children (5–17 years of age) died by suicide at a rate of 9.3 deaths per 100,000 persons, compared to 1.8 per 100,000 for non-Aboriginal people, and accounted for 27% of Australian children who died by suicide between 2011 and 2015. Adding concern to these already high figures is the widely held belief that suicide rates are an underestimate of the true values. For Aboriginal suicide deaths specifically, this is likely attributed to “issues relating to identification of race and cause of death” (Hunter 2007, p. 90). Tatz (2001) suggests that actual suicide rates might be at least two to three times greater than the official recordings. Further, Hunter and Milroy (2006) caution that rates of suicide have changed over time and

also differ between communities, indicating the need for an ongoing effort to understand this issue for suicide prevention to be effective.

Although there is a paucity of research exploring the heightened risk of suicide among Aboriginal communities (De Leo 2012), or Aboriginal experiences of suicide (Elliott-Farrelly 2004), many explanations and contributing factors have been proposed. While some of the factors, such as substance use and unemployment (Hanssens 2007; Silburn et al. 2010), are also associated with suicide deaths of non-Aboriginal people, numerous authors have described the unique contributors to suicide for Aboriginal people. In his book, *Aboriginal Suicide is Different*, Colin Tatz, a leading author in this field, urges: “To understand Aboriginal suicide, one has to understand Aboriginal history” (Tatz 2001, p. 8). This understanding encompasses a wide range of issues, including: persistent loss and grief resulting from a history of colonization and intergenerational trauma (Tatz 2001); disintegrated cultural identity (Tatz 2001); loss of connection to culture and land (The Elders’ Report 2014); an ongoing cycle of grief associated with suicide and other deaths (Tatz 2001; Silburn et al. 2010); scarcity of role models and mentors, particularly for young people (Tatz 2001); and racism (Silburn et al. 2010; The Elders’ Report 2014). Hunter and Milroy (2006, p. 150) summarize the combined impact of these factors:

Considering life as a narrative or story, the desire to end one’s personal story abruptly, prematurely and deliberately can be seen to stem from the complex interplay of historical, political, social, circumstantial, psychological and biological factors that have already disrupted sacred and cultural continuity; disconnecting the individual from the earth, the universe and the spiritual realm – disconnecting the individual from the life affirming stories that are central to cultural resilience and continuity.

This highlights the important need for Aboriginal social and emotionally well-being research to consider the interconnectedness between cultural, spiritual, social, and physical influences (King and Brown 2015), in contrast to the more biomedically focused approach adopted in Western understandings. For example, for Aboriginal people, the term mental health comes more from an illness or clinical perspective, implying a greater focus on the individual (SHRG 2004). Instead, the term “social and emotional well-being” is preferred, which is considered to differ in important ways to non-Indigenous concepts of “mental health” (SHRG 2004). Social and emotional well-being recognizes the importance of connection to land, culture, spirituality, ancestry, family, and community (SHRG 2004), with these factors serving as sources of strength and recovery when Aboriginal peoples experience stress and adversity (Kelly et al. 2009).

The impact of suicide on Aboriginal communities has received little attention, but is being increasingly recognized as an important area for research. With profound, ongoing implications for individuals, families, and communities (Department of Health and Ageing 2013), it is not surprising that suicide results in persistent experiences of bereavement (Tatz 2001), with grief and mourning often spreading between communities, particularly where families and communities are interconnected, and where cultural obligations exist, such as funeral attendance and

observance of “sorry business” (Silburn et al. 2010). For many, the frequency of deaths – through suicide and other causes – often means that the grieving process is cut short, resulting in complex trauma experiences, with families and communities experiencing an ongoing state of mourning, grief, and bereavement (Silburn et al. 2010). In addition, suicide “clusters” are not uncommon, particularly among young people (Hanssens 2007), whereby one suicide in a community can spark more, often with the same method and by people of the same gender and similar age of the deceased (Elliott-Farrelly 2004). This creates a perpetual cycle of grief.

3 Awareness of the Historical Research Context

A culturally competent approach requires awareness of and sensitivity toward the historical context of research with Aboriginal people and communities more broadly. As non-Aboriginal researchers, we came into this space with a consciousness toward the historical relationships between Aboriginal and non-Aboriginal Australians. We have continued to remain aware of, and feel concern for, this historical context, so as not to perpetuate power imbalances or other negative outcomes during our interactions with Aboriginal peoples.

Our awareness of the historical relationships between Aboriginal and non-Aboriginal Australians also extends to the research process itself, as explained by Laycock et al. (2011, p. 5):

This history of research for Indigenous peoples is tied to the history of colonisation. In the eighteenth and nineteenth centuries, Europeans explored and ‘discovered’ other worlds, expanded trade and established colonies. Western scientific thought developed. As Indigenous peoples were systematically colonised, their societies and cultures began to be studied from the point of view of groups with more power and privilege, and with different systems of knowledge.

This historical approach to research has been viewed as unhelpful for addressing Aboriginal experiences and concerns (Humphrey 2001). It is not surprising, then, that research can be viewed as serving academic interests rather than benefiting Aboriginal health (King and Brown 2015), and that Aboriginal people have been critical of the research undertaken on their communities and cultures (Humphrey 2001), skeptical about its usefulness (Greenhill and Dix 2008), and hesitant to participate (Ralph et al. 2006).

Although there has been a gradual shift away from this approach where Aboriginal people are seen as “subjects” of research and a movement toward a more collaborative focus (Ralph et al. 2006; Laycock et al. 2011), having this awareness is important for understanding the potential perspectives of the people and communities we engage with during the research journey. Concerns about conducting work against a backdrop of political and social exploitation are not uncommon for researchers working in the cross-cultural space (Liamputtong 2008, 2010). Greenhill and Dix (2008) highlight how having a consciousness toward this history of research

can challenge researchers to continuously work toward building relationships, engage in respectful interactions, and harbor a willingness to learn. This emphasizes the need for collaboration, consultation and relationship building (see also ► [Chaps. 15, “Indigenist and Decolonizing Research Methodology,”](#) ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research,” and ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze”).

4 Understanding and Applying Ethical Research Principles

Against a history of poor research practices, including exploitation, with Aboriginal communities, the 1970s saw the emergence of Indigenous activism in research. This was evidenced, for example, by the drafting of research guidelines, which called for “Aboriginal control of, and participation in, research, the adoption of non-invasive and culturally sensitive methodologies, the pursuit of research of need and benefit to communities, and full Aboriginal control over the dissemination of findings” (Humphrey 2001, p. 198). By the 1980s, this led to the formalization of ethical research guidelines (Humphrey 2001).

In Australia, there are several guidelines which specifically address ethical research practices when working with Aboriginal communities, and researchers should endeavor to understand and apply these from the outset. These guidelines include the National Health and Medical Research Council’s (NHMRC 2003), *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (Values and Ethics)* and *Keeping Research on Track*, which was developed by the NHMRC in 2005, translating *Values and Ethics* into a community guide for participating in research.

Culturally competent research requires an understanding of the ethical principles underpinning research with Aboriginal peoples, irrespective of the topic of interest. There are six core values considered important to all Aboriginal and people – spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility (as defined in *Keeping Research on Track*). While specific values and protocols vary between societies, these core six are considered common to all, and “each community or organization has the right to express how these core values, and any unique values, will be addressed in research” (NHMRC 2005, p. 8). The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and The Lowitja Institute (2013, p. 9) summarize these six core values:

- **Spirit and integrity:** A connection between the past, present, and future, and the respectful and honorable behavior that holds Aboriginal values together.
- **Reciprocity:** Shared responsibilities and obligations to family and the land based on kinship networks, also includes sharing of benefits.
- **Respect:** For each other’s dignity and individual ways of living. This is the basis of how Aboriginal peoples live.
- **Equality:** Recognizing the equal value of all individuals. Fairness and justice, the right to be different.

- **Survival and protection:** Of Aboriginal cultures, languages, and identity. Acknowledging shared values is a significant strength.
- **Responsibility:** Is the recognition of important responsibilities, which involve country, kinship, caring for others, and maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person or any place. Responsibilities can be shared so others can be held accountable.

Both the NHMRC's *Values and Ethics* and *Keeping Research on Track* are currently being reviewed. In an examination of ethical guidelines for research with Aboriginal communities, *Researching the Right Way*, AIATSIS and The Lowitja Institute (2013) note that both NHMRC documents have been developed with a view to *prevent* unethical practices in health research involving Aboriginal peoples. In contrast, Jamieson et al. (2012) developed a set of guidelines which aim to *promote* ethical practices in research among Aboriginal populations, based on best practice from their own experience and the literature (AIATSIS and The Lowitja Institute 2013). Table 1 presents the five essential principles relevant to health research and suggestions for how these could be applied to a culturally competent approach to suicide research with Aboriginal peoples. These ethical principles, and those outlined by the NHMRC (2003), should be used as a guide throughout the research journey, from project conception to dissemination of results (Laycock et al. 2011).

5 Cultural Competency Throughout the Stages of the Research Journey

The Lowitja Institute, Australian's National Institute for Aboriginal and Torres Strait Islander Health Research, provides a range of valuable resources for conducting research in this area. This section draws attention to some of the key stages in the research journey, and readers are encouraged to consult The Lowitja Institute resources for additional information.

5.1 Developing Relationships

Trustworthy and respectful relationships are integral to research that is both meaningful and sustainable. This involves relationships with collaborating organizations and researchers, as well as research participants themselves. Preferably, research priorities will be identified by, or through collaboration with, Aboriginal communities (Laycock et al. 2011). A commitment to partnering with Aboriginal communities helps to ensure that research is developed from the ground up and contributes to building capacity to develop and implement programs within the community of interest. Elliott-Farrelly (2004) highlights the various benefits that can result from suicide prevention programs that have been both developed and implemented by the Aboriginal communities they are targeting, including: heightened personal and

Table 1 Key principles of research and application to practice for ethical, culturally competent approaches to suicide research

Essential principle (Jamieson et al. 2012)	Application to practice in culturally competent approaches to suicide research with Aboriginal peoples
Addressing a priority health issue as determined by the community	Addressing issues which have been determined by the community ensures that research focuses on issues that are of most importance – and which are likely to lead to the most benefits – to address the health and well-being of Aboriginal peoples. Suicide has been identified as a priority by numerous leaders within Aboriginal communities (e.g., The Elders' Report 2014), as well as peak bodies representing Aboriginal people, e.g., Aboriginal Health Council of Australia (King and Brown 2015). Community identification of priorities for research, such as in the area of suicide, also helps to foster community ownership and build relationships
Conducting research within a mutually respectful partnership framework	Respectful relationships characterized by openness, trust, and transparency underpin research with Aboriginal communities that is successful and mutually beneficial (AIATSIS and The Lowitja Institute 2013). Building such relationships can take considerable time and involves genuine commitment on the part of researchers. The burdens and benefits of research should be distributed equitably. At the outset of a project, researchers need to work closely with communities to make joint decisions on various arrangements. In the sensitive area of suicide research, arrangements to ensure Aboriginal peoples are provided with sufficient support to participate and are protected when necessary, throughout the research process, are critical
Capacity building is a key focus of the research partnership, with sufficient budget to support this	Just as the capacity building of communities to take action in response to suicide is important (Department of Health and Ageing 2013), building the capacity of Aboriginal people as researchers and consultants in this area is vital. Working in partnership with Aboriginal people and communities provides opportunities for empowerment and to build their own research capacity (King and Brown 2015). Importantly, Aboriginal peoples bring unique knowledge and understanding, distinctive to their communities and history, which contribute significantly to the evidence base (Department of Health and Ageing 2013). As community engagement is a key aspect in any such

(continued)

Table 1 (continued)

Essential principle (Jamieson et al. 2012)	Application to practice in culturally competent approaches to suicide research with Aboriginal peoples
	research (Gwynn et al. 2015), particularly in an under-researched area such as suicide, it is important for researchers to factor in additional time and community engagement activities when budgeting for projects in this area
Flexibility in study implementation while maintaining scientific rigor	In the sensitive area of suicide research, it is critical that researchers remain flexible throughout the research process and are prepared to: “tread carefully if the research concerns sensitive issues or is likely to occur at crucial time of life” (King and Brown 2015, p. 9). For example, being sensitive toward rituals related to loss and grief, e.g., “sorry business,” means that research may need to be postponed. The choice to not participate or withdraw participation should be respected at all times
Respecting communities’ past and present experience of research	It is important that researchers are mindful of the context in which suicide research occurs – in particular the history of research that has taken place with Aboriginal peoples. Understanding wider sociopolitical, historical factors are also vital to research in this area (Tatz 2001)

community awareness, increased self-respect and dignity, higher levels of commitment to achieve desired outcomes, decreased dependency, and empowerment.

In some situations, relationships will already exist between non-Aboriginal researchers and Aboriginal communities. However, this may not be the case and developing relationships may be a new experience. In these instances, relationship building may initially seem an elusive task, particularly in situations where the researchers have a few, or no, existing relationships with Aboriginal peoples or the Aboriginal health sector, or in the area (geographic or subject) where they are conducting the research. For any researchers, Aboriginal Community Controlled Health Organizations (ACCHOs) can be an important starting point for building relationships.

Central to relationship building should be respect and understanding for what each person or community brings to the research – whether that be knowledge, perspectives, skills, experiences, or ways of working (Laycock et al. 2009). This can be achieved through openly discussing what each person, organization, or community would like to contribute, and being open to this changing as the project progresses. Consideration should also be given to when and where meetings take place. In some instances, external pressures, such as funding, limit the time that can be allocated to this process. However, efforts should be made to factor this in to the early stages of the research

project. This might involve, for example, informal meetings (e.g., over coffee) for different parties to get to know one another and begin to build rapport, before specific research agendas are discussed. We see this as an ongoing process, and something that continues over time, between individual projects.

5.2 Deciding on a Research Topic

Until more recently, research topics exploring Aboriginal suicide have largely been developed and investigated from a Western, positivist perspective. Reflective of trends in suicide research more broadly, these studies have typically sought to understand rates and prevalence (e.g., Clayer and Czechowicz 1991; Cantor and Slater 1997; Parker and Ben-Tovim 2002; Pridmore and Fujiyama 2009; De Leo et al. 2011; Luke et al. 2013; Soole et al. 2014), methods (e.g., De Leo et al. 2011; Soole et al. 2014), and place of suicide (Soole et al. 2014). Similarly, risk factors have received attention (Clough et al. 2006; Silburn et al. 2010; Calabria et al. 2010; Jamieson et al. 2011; Priest et al. 2011; Zubrick et al. 2011; Luke et al. 2013; Soole et al. 2014). Less emphasis has been placed on understanding suicide from the perspective of Aboriginal peoples (Lindeman et al. 2014), how suicide might be prevented (Capp et al. 2007; Lopes et al. 2012), or how effective prevention programs are (Harlow et al. 2014; Ridani et al. 2015).

It should now be clear that research priorities should be set by the people to whom they relate (King and Brown 2015). These priorities can be identified through consultation and collaboration with individuals, communities, and the ACCHO sector, as well as through an awareness of the policy context. For example, the National Aboriginal and Torres Strait Islander Suicide Prevention Strategy (Department of Health and Ageing 2013) reflects calls for unique approaches to understanding and addressing this issue (e.g., Tatz 2001; Elliott-Farrelly 2004; Procter 2005), and was developed through extensive community consultation, Australia-wide. At its heart, the policy “has a holistic and early intervention focus that works to build strong communities through more community-focused and integrated approaches to suicide prevention,” with an emphasis on Aboriginal people developing “local, culturally appropriate strategies to identify and respond to those most at risk” (Department of Health 2014, p. 2). Two of the six key action areas are to build on strengths and capacity in communities, and to build strengths and resilience in individuals and families. The policy’s explicit focus on strengths-based approaches was confirmed more recently during the first National Aboriginal and Torres Strait Islander Suicide Prevention Conference, held in 2016, where there was an emphasis on the need for strengths-based, community driven solutions to suicide (Finlay 2016).

5.3 Applying an Appropriate Research Methodology

The focus on positivist research to date has favored quantitative methodologies in suicide research, such as retrospective analyses of death records. This emphasis

means that Aboriginal understandings of suicide have predominantly been excluded. Further, these approaches can be viewed as ignoring the diversity of Aboriginal people and communities (King and Brown 2015). As such, qualitative approaches are seen to be more favorable, and Laycock et al. (2009, p. 6) highlights how:

some research approaches are better suited to Indigenous health research than others. Collaborative, participatory and multidisciplinary research approaches are often used in community settings because they provide more opportunities for communities to set priorities and guide research processes, to build Indigenous ways of doing things into the project and to 'privilege' the voice of Indigenous participants.

While peer-reviewed qualitative research on this topic is sparse, examples can be seen in the gray literature. For example, The Elders Report (2014) incorporates voices of 31 elders from over 17 communities in Western Australian, Queensland, and the Northern Territory, who have experienced the impacts of suicide in their communities, and who offer solutions for how to best address it. Despite the diversity of experiences of each individual, some common themes were identified, including the important healing and protective role of culture.

Tsey and colleagues (2007) describe the development of several empowerment-based research methodologies to improve the social and emotional well-being of Aboriginal people, including participatory action research (PAR). Research approaches such as PAR seek to shift unequal power relations between participants and researchers as participants become researchers in their own right to address issues of concern that are a priority to them (Tsey et al. 2007; Liamputtong 2013; Higginbottom and Liamputtong 2015). This approach can offer a range of benefits for participants, including increased personal empowerment and control over their lives and situations, stronger and longer-term research partnerships which are based on mutual respect and trust, and more sustainable outcomes which are driven by the priorities of communities (Tsey et al. 2007). In some situations, research projects may involve participants from a range of backgrounds and sectors, and it may not be possible to develop a methodology that best suits all participants. In these instances, a mixed-methods approach could be considered. For example, while our recent research included a survey component, it also involved an opportunity for participants to engage in qualitative interviews.

5.4 Seeking Ethical Approval

Ethics approval is an important process in any research (Ramcharan 2017; see also ► Chap. 106, "Ethics and Research with Indigenous Peoples"). For projects involving Aboriginal people and communities, approval should be sought from an Aboriginal Health Research Ethics Committee (AHREC). Engaging with AHRECs should not be viewed as simply a process in the research journey, but also as an opportunity to ensure the safety of the proposed research and to strengthen the research plan. In our experience, this process has been invaluable for building new connections with

the ACCHO sector, ensuring the cultural appropriateness of the content of our suicide prevention training program, and promoting the research to interested participants. These processes have been essential for ensuring steps were taken to maximize opportunities for participation.

5.5 Engaging with Research Participants

Researchers should be aware that although there has been a long history of research “on” Aboriginal people, many Aboriginal people may not have had experiences being involved in research and may not have a clear understanding of the process (e.g., their rights regarding participation). As with any research, researchers have a responsibility to facilitate this understanding. Examples of how this can be achieved include: recruiting participants in collaboration with the aforementioned ACCHOs; providing participants with access to *Keeping Research on Track*; developing research materials (e.g., information sheets and consent forms) using appropriate language (Liamputtong 2008, 2010); and being available and approachable to discuss the research. In our experience of recruiting participants for a community-based suicide prevention education project across rural South Australia, valuable reciprocal conversations were had when individuals phoned to express an interest in participating, rather than doing so by email. Participants were able to ask questions about the research project, and we were able to learn more about their community prior to meeting in person during the intervention and data collection.

Steps can also be taken to demonstrate cultural sensitivity toward participants, communities, and culture throughout the implementation of research. For example, during our suicide prevention training program, our team’s Aboriginal and Torres Strait Islander Project Coordinator made efforts to organize a Welcome to Country by an Elder or other recognized community leader in each town, where possible. Further, the team agreed that cultural considerations for health professionals working with Aboriginal people should be discussed early in the training days, rather than added towards the end of the day.

5.6 Reporting and Disseminating Findings

Researchers need to give careful thought to how the findings from research with Aboriginal people will be reported and shared. In particular, the types of reports or strategies used to disseminate research needs to be considered, including whether a combination of approaches is more appropriate. Researchers should engage with people or organizations connected to the communities, as early on as possible, to share decisions on aspects such as: processes for involving community members in the design of reports and other mediums for presenting findings; whether consent needs to be sought to present aspects of the findings, e.g., use of photos; and who needs to be acknowledged in reports and other approaches to dissemination (NHMRC 2005). Research findings should be delivered in way that is

understandable and accessible, with the NHMRC (2005) recommending that a Plain English Community Report should be made available.

6 Conclusion and Future Directions

It is clear that despite enormous strengths and resilience among Aboriginal peoples, suicide is an ongoing, complex concern and can have profound consequences. It is critical that researchers in this space remain conscious of the ongoing impacts of colonization and intergenerational trauma for Aboriginal peoples, and be open to a holistic understanding of social and emotional well-being. Similar to research related to other aspects of social and emotional well-being, to date, research into suicide among Aboriginal communities has been limited by being primarily undertaken from a positivist, Western perspective. This chapter has outlined the need for a culturally competent approach to research with Aboriginal people and communities, through all stages of the research process. Although discussed in the context of suicide, the principles described in this chapter apply to a range of sensitive topics, including other social and emotional well-being and health concerns. Similarly, these are not specific to researchers working in Australia, but could be considered when working with Indigenous peoples in other parts of the world (e.g., Canada and New Zealand). Across this range of sensitive topics and participant groups, researchers are encouraged to strive for ongoing cultural competency, with an emphasis on projects that have been developed by, or in collaboration with, the communities in which they hold relevance, and through adopting a participatory, strengths-based approach. Working together, Aboriginal and non-Aboriginal researchers have important roles to play in progressing the research agenda on the sensitive and complex topic of suicide. Conducted in the spirit of respect, shared goals, and shared responsibilities, ongoing partnerships can lead to achieving mutual understanding, joint capacity building, and research processes which not only are sustainable but also have positive impacts for Aboriginal people, families, and communities.

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Visual Methods in Research with Migrant and Refugee Children and Young People

99

Marta Moskal

Contents

1	Introduction	1724
2	Children as Social Agents	1724
3	Participatory Methods with Children and Young People	1725
4	The Use of Visual Methods as Participatory for Children and Young People	1726
5	Collecting and Analyzing: Migrant and Refugee Children's Images in Research	1728
5.1	Maps and Drawings	1728
5.2	Photographs and Videos	1732
6	Conclusion and Future Directions	1734
	References	1735

Abstract

This chapter examines how visual methods have been used in understanding and interpreting children's worlds. Focusing on social sciences engagement with diverse visual methods (like drawing, maps, photographs, and videos), the chapter contributes to the discussion about their value and limitations. The chapter broadly reviews the body of knowledge on the use of children's images in research. It provides some references to the research in health social sciences, however, focuses particularly on migrants and refugees. Although visual images play a meaningful role in the lives of young people, social sciences still privileges approaches based on words and numbers. Children's visual methods, however, are gaining increasing interest as many social scientists search for methods that align with the current conceptualization of children as social agents and cultural producers. It has been argued that visual methods can secure participant

The chapter has been developed based on the paper (Moskal 2010).

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1723

engagement and reflexivity among a group who may not be comfortable with a traditional survey, interview, or focus group methods. Exploring specific examples of the studies with migrant and refugee children and young people, the chapter demonstrates how visual methods can be evaluated as a research strategy.

Keywords

Visual research · Participatory research · Migrant and refugee children · Research with young people · Children's perceptions of health and illness

1 Introduction

This chapter focuses on visual research methods that could be effective in research with children and young people who have experienced transitions involved in forced or voluntary migration and resettlement. Researching migrants and refugees in global times requires an approach able to reach into people's transient, volatile lives, understanding the complexity of multiple places, and diverse cultural and intellectual heritages (Alasuutari 2004). Particularly in the migration and refugee context, the research has focused on health indicators and schooling rather than on children's everyday lives, and has used traditional research tools such as structured questionnaires and focus group interviews. As a result, there are only small number of studies that document their lives as told in their own voices (Oh 2012, p. 282). There has been an increased interest in research processes that are child-oriented, and which model participatory research designs that place children at the center of the process as active participants. This has particularly been the case of qualitative research methods that are designed to examine children's experiences and perspectives, especially about children in vulnerable situations such as from refugee or migrant backgrounds (see Crivello et al. 2009; Due et al. 2014). In a process of a wider re-evaluation of research with children and young people (Lewis et al. 2004; Christensen and James 2008), visual, participatory methods have become increasingly used. Researchers and practitioners across a range of disciplines employ them as a means of exploring the children and young people's experiences, relationships, and lifestyles (Hart 1992; Barker and Weller 2003; Thompson 2008).

2 Children as Social Agents

This chapter sees children as competent beings whose views, actions, and choices are of values (Alanen and Mayall 2001; see also ► Chap. 115, "Researching with Children"). This refers to the recent scholarship of human geography, social anthropology, and sociology of children and childhood that treats children as active participants in their own socialization (Zelizer 1985; James et al. 1998; Johnson et al. 1998; Orellana 1999; Punch 2002; White 2002). I explain how this approach extends to visual research methods.

Over the past 20 years, many social scientists begin to view minors, as not merely the reproducers of culture, but as “cultural agents and social actors in their right” (Mitchell 2006, p. 60). For children to be able to participate in research, it might be necessary to develop different nonadult centered methods (Mitchell 2006). Boyden (2003) suggests a need for “age-appropriate” methods that “empower children” and lead to “valid child-led data.” Mitchell (2006) argues that visual methods are said to be “child-centered” in the sense that they may be familiar, even enjoyable to the child. When activity is familiar and pleasant to the child, it can be particularly “useful in bringing out the complexities of their experience” (Nieuwenhuys 1996). Although they have been promoted as a corrective to the disempowering positivism, the child-centered methods, including visual methods, have been criticized for limiting the research to the level of individual child perception and being unable to account adequately for the ways in which political and social forces work to shape children’s lives (Ansell 2009; Marshall 2013). However, following Ansell, I argue that visual, participatory methods with children and young people have a potential take into account wider social and political contexts (Ansell 2009; Mitchell and Elwood 2012; White et al. 2012).

In my research with migrant children and young people, drawing, mapping, and storytelling were used to understand the ideas and practices of home and belonging among transnational families in Scotland (Moskal 2010, 2015). These child-centered methods helped to reveal how children and young people experience mobility and construct a sense of home while resettling. The stories help us to look at and simultaneously interpret the local and the global experiences of participants. Children’s involvement in migration upsets the notion of children as innately local beings and clearly illustrates how children’s everyday lives are shaped by structures and constraints originating beyond the local scale. By viewing children’s agency as a process, Ansell (2009, p. 194) argues that “too often local, concrete and agency are conflated into an acceptable focus for research, in opposition to a global, abstract or structuralist perspective that is viewed with suspicion as too ‘distant’ from real children.” I demonstrate how children’s stories seem to destabilize the dualism of the global and local (using Massey’s 2005 idea) as the transnational social spaces in which they live continue to shape their social relations, cultural practices, and identifications (Moskal 2015).

3 Participatory Methods with Children and Young People

The participatory practices start from the beliefs that young people have the capacity to express themselves and the right to do so and that expressing themselves can include visual means (Thompson 2008; see also ► Chaps. 100, “Participatory and Visual Research with Roma Youth,” and ► 117, “Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization”). There has been increasing emphasis, within the social sciences, on working participatory with children so that they might define research agendas and participate in fair ways (Thompson 2008; Lomax 2012). The participatory research is

increasingly associated with the rapid growth in the application of an immense range of creative and visual methods including photography and video walking tours, mapping, and art-based approaches such as drawing and collage. This makes a substantial and genuine attempt to include children in the production of knowledge where previously their experiences have been marginalized or absent (Lomax 2012).

Lodge (2009) insists that images used in research require the participation of young people to provide contextual information to make meaning. She further argues that this is one of the most emancipatory aspects of using images in research because to understand or read the images we need the participation of the young people who produced them. Importantly, child-centered methodologies are not focused solely on what may be meaningful to a child participant, but what is meaningful to larger contexts of children's lives.

4 The Use of Visual Methods as Participatory for Children and Young People

Visual methods present several advantages as participatory methods for engaging children in research. Therefore, they are being used creatively in diverse social and cultural contexts. For example, to explain children's perspectives on health and illness (Geissler 1998b; Ross et al. 2009; Fernandez et al. 2015), poverty (Sime 2008), tourism (Gamradt 1995), identity (Cowan 1999), identity and consumption (Croghan et al. 2008), time (Christensen and James 2000), and place and belonging (Orellana 1999; den Besten 2010). There are many ways of collecting visual data, and the choice of method depends on the aims and theoretical perspective of the researcher (Bagnoli 2009). This may include drawings (e.g., Geissler 1998a, b; Guillemín 2004; Van Blerk and Ansell 2006; Fernandez et al. 2015; Liamputtong and Fernandez 2015), maps and diagrams (e.g., Bromley and Mackie 2009; Moskal 2010; Copeland and Agosto 2012), and photographs and videos (e.g., Radley and Taylor 2003; Tinkler 2008; Due et al. 2014; Marshall 2013).

Visual methods can be used alone, in combination with verbal data or as one of some multisensory methods. For example, Bagnoli (2009) describes the use of multimethod biographies to holistically explore young people's identities. Methods included oral interviews, written diaries, and visual methods such as self-portraits, video diaries, relational maps, and diagrams. The aim is not only to use visual methods as a tool to assist with interviews but as an important method of eliciting and understanding experience in its right (Bagnoli 2009; see also ► Chap. 71, "Self-portraits and Maps as a Window on Participants' Worlds"). Visual research offers an accessible way for young people to become active in the research process themselves, to reverse the typical role of having research done to them, and to allow them to participate more in this process (Thomson 2008). Lodge (2009) claims that the creation of images (drawings, video, or photography) can offer opportunities for the usually silenced and marginalized to participate, and perhaps to alter prevailing power relationships. She gives an example of the project by Kaplan and Howes

(2004) who describe the creation of a contact zone (a website) where differently empowered people – teachers and students – could interact. As their project's title suggests "Seeing through Different Eyes" invites participants to consider alternative views and meanings through dialogue about images produced by young people. Sometimes, using images created by young people will challenge accepted wisdom and assumptions underpinning practice in schools (Lodge 2009).

Likewise, Geissler et al.'s (1997) study with Luo schoolchildren in western Kenya showed that the children confronted in school with entirely different traditions of health knowledge without relation to their daily life and the experience of illness and healing. Geissler (1998b, p. 133) suggested that the children moving at the interface of indigenous knowledge conveyed informally in the family and biomedical ideas, mainly transmitted in school, are creatively contributing to the integration of old and new and actively shaping their ideas about health and the body. In Geissler's study, drawing was used together with the written narrative ("composition"). The children were asked to draw images of the body and its inside, partly on paper and partly with sticks in the sand in the schoolyard. The same children were asked to write compositions in Dholuo (local language) on the topic of "worms." Both compositions and body maps proved very useful in that the children enjoyed their tasks and felt more confident than in the immediate face-to-face interview. Body maps, demanded the creation of some order in space rather than in time, giving different insight (than written and oral expressions) into how the children thought about worms (Geissler 1998b).

Listening to children's ideas about worms and their role in the body, Geissler (1998b) showed that the children active contribution to the creation of medical culture. The children's drawings and written narratives demonstrate that "Luo medical culture" is dynamic, open to innovation, and draws on all available sources of knowledge that can render experience coherent and guide action. Thus, the Luo children are agents of cultural production at the interface of different kinds of medical knowledge and not mere recipients of prefabricated health messages.

The value of visual methods as a catalyst for more conventional interviewing techniques was reflected, for example by Bromley and Mackie (2009) who found the mapping task was useful for prompting discussion with street working children in Peru. Bromley and Mackie (2009) employed a mapping task (along with a card selection game and interview) to explore the experiences of these children. The mapping work required no literacy or verbal skills and therefore was the most suitable for working with street children as it enabled all of them to express themselves fully. The second phase of the task did demand some oral skills in giving reasons for the patterns, so explanations varied in detail. The mapping work firstly sought to determine the specific locations where the children liked and disliked working. It also aimed to investigate why children have such preferences. A basic map of the city center was drawn, and a copy was given to the children. Each child was given two colored pencils, and they were asked to color in red the locations where they like to trade and in blue the locations where they do not like to trade. Once the child was happy with their map, they were asked to explain why they had used specific colors in particular locations and these explanations were recorded on the map (Mackie 2011). The authors reflect on the process saying that the mapping

task not only prompted for discussion but, in contrast to an interview, gave the children time to think, rather than give a spontaneous response. Thus, the finished product was a more accurate representation of the child's opinions.

To summarize, these methodological considerations, researchers in diverse disciplines have sought research methods that may be particularly well suited to working with, rather than "on" children. Enabling children's perspectives through image can make their knowledge and concerns visible to adults and can be the basis for involving children in identifying and solving issues that affect them. In my research among migrant children in Scotland, drawing was a strategy to collect the research material itself and to facilitate the narrative interviews, especially with the younger children. In the next session, I detail and evaluate these drawing activities.

5 Collecting and Analyzing: Migrant and Refugee Children's Images in Research

5.1 Maps and Drawings

Several studies (e.g., Dockett and Perry 2005; Einarsdottir et al. 2009) have used drawings to capture children's knowledge and experience. However this approach has been relatively scarce in migration research (the exceptions include Mitchell 2006; Van Blerk and Ansell 2006; White et al. 2012; Fernandez et al. 2015; Liamputtong and Fernandez 2015). Mental maps have been used in research with migrant children, for example by den Besten (2010), to describe their local, urban experience in order to map out the fears and dislikes in Berlin and Paris.

In my research on the experiences of families and children of Polish migrants in Scotland (Moskal 2010, 2015; Moskal and Tyrell 2016), children and young people (between the ages of 5 and 17) participated in individual and small group interviews as well as drawing and mental map making. Children drew maps from memory that helped outline their spatial awareness, the locations of their activities, as well as a sense of belonging to the particular place. Participants, sometimes, had difficulty constructing their maps, and this was based on a lack of spatial concepts among the children. Perspective, symbolization, and other standard map qualities were very rarely observed. However, some of the children demonstrated the use of national symbols, namely the Polish and Scottish flags. I did not ask participants to focus on particular localities. The mental maps produced a wide diversity of images regarding the number of elements included and the perspective taken to show the varied childhood experiences as well as the organization and meaning of migrant childhood (Anning and Ring 2004).

Lynch (1960) claims that most often our perceptions of a locality are not sustained, but are fragmentary and mixed with other concerns. His assertion resonates with the migrant children's images of the localities they were in. For example, Kate, aged nine, drew a subjective map (Fig. 1) representing one street, along which she placed her house and school in Edinburgh next to her home, garden, and playground in the Polish town that she came from. Kate's everyday routines and practices marked a way for her to bridge the gap between past and present, and between



Fig. 1 Kate's mental map

here and there. Kate's map illustrated this particular sense of connection and a sense of temporary belonging. Kate's map evidences that children are able to imagine translocal life, as opposed to a transnational life. The similarities she perceives between her Polish and Scottish places of residence constitute a powerful translocal tie and do much to make her feel at home when she is abroad. This type of evidence emphasizes the importance of different sites of belonging, connected with the various spheres of life that children encounter. Children's lives are not necessarily statically attached to their physical experience of space because they can imagine distant places and the process of moving between places (Van Blerk and Ansell 2006).

The awareness that people and places "back home" were changing while they were not there was unsettling for some children (see Moskal and Tyrell 2016). The family is crucial in the children's and young people's constructions of home and belonging, regardless of whether they refer to the family back in their country of origin, the family in their current place of residence, or in both places. In a second technique, children were asked to draw a tree with roots and then to draw or write beside the roots the things that they were attached to.

This activity also resulted with the drawings demonstrating a sense of connection with the home country that exists in reality (Internet conversations, phone calls, more or less frequent visits to and from the country of origin) but also in the imaginary realm. "I drew the phone to call my family in Poland and a computer to talk to them," said 10-year-old Vicky to describe her drawing (see Fig. 2). Then, she explained further:

I have got four cousins and grandma and granddad and three aunts and three uncles and many friends in Poland. We call often grandparents and I talk with my friends on Skype and there is one friend from Poland who went to Ireland and I contact her by Skype too.

The material objects, phone and computer, present on Vicky picture, were not unique as many participants drew the same objects under their trees of attachment or inside of their houses on the mental maps. For example, in his house Mathew,

Fig. 2 Vicky's tree of attachment



8 years old, drew himself next to the computer with a person and phone on the screen (see Fig. 3). These are “material and imaginative” aspects of these representations, which show that communication, social relations always stretched beyond their localized presence. The very coexistence of closeness and remoteness is what makes the position of migrant children and their families problematic at all times. Spatial proximity is involved in terms of the immediacy of family members and friends, but at the same time home includes spatial distance. Children defined homes by the inclusion of various elements (people) but also by what or rather who was absent.

Letting the children create more than one drawing was a way to allow them to express multiple ideas about themselves; however, some children chose to make only one drawing or were tired after the first drawing. Younger children sometimes did not understand the concept of the thematic drawings or deviated somewhat from the instructions (e.g., drawing a tree with some significant things around it), or they

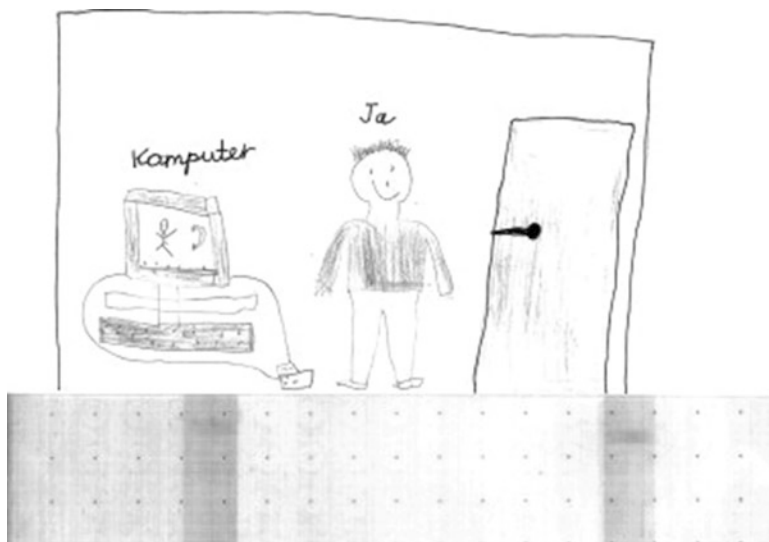


Fig. 3 Matthew's inside of his house

asked for another sheet of paper to draw something entirely different – whatever they felt inspired to draw.

Strict visual analyzes without the ability to engage with the child seem to be difficult when we try correctly identify the images on the drawings and to determine the most important features. This is an important methodological issue, as visual data collection strategies can become so “child-centered” that the researcher has difficulty with interpretation. Therefore, in this study, pictures were used to prompt more detailed oral information, keeping the images as the central reference point. I also ask the capable children (excluding those over 8 years old) to sign the drawn objects. To connect a drawing to the social life, intent and interests of its producer, the analysis of drawings should move reflexively between “the image and verbalization” (Harrison 2002, p. 864). In working with children, embedding the analysis of an image within its producer’s account of that image is especially relevant since it is often assumed that children need someone to speak for them. However, as with adults, children vary in their ability and inclination to talk about their visual productions. My general experience was that children were willing to describe the elements of their drawings verbally, but rich narrative accountings were uncommon. There were few examples of the children who did not want to talk. This observation highlights more than children’s differing communicative competence or the ethnographic fact that adults rarely ask for children’s opinions in this community. Drawings are not a substitute for children’s voices and the absence or muting, or fragmentation of children’s speak about their images means researchers need to be particularly cautious about overinterpreting their images. Therefore, I placed greater importance on using the maps and the drawings as “catalysts for further oral discussion” to properly interpret the images. However, children are not used to interviews, so the structure of the interviews

depended on the particular child, and its ageless structured interviews were conducted with younger children. Therefore, for individual interviews with young children, even children as young as 5 and 6 years olds, the drawings were essential to provide a point of reference and to enable communication.

5.2 Photographs and Videos

Photo-elicitation methodologies commonly introduce photographs into a research interview to obtain information (Harper 2002). In photo-elicitation, pictures are used to drive the conversation, to evoke more and different hint of information than in the interviews using words alone. Croghan et al. (2008) suggest that the photo interview offers young people an opportunity to show rather than “tell” aspects of their identity that might have otherwise remained hidden. It may therefore be a useful tool for researching contentious or problematic identity positions. Croghan et al. (2008) have also argued that the features of visual representation influence the versions of young people’s identity that are presented. Photo-elicitation differs from photovoice approach, which is the community-based participatory research method also known as “participatory photography” (see also ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method”). Photovoice was developed by Wang and Burris (1994) who created “photo novella,” now known as photovoice, as a way to empower rural women in China to influence the policies and programs affecting them. Applying photovoice to public health promotion, the authors describe the photovoice methodology and analyze its value for participatory needs assessment (Wang and Burris 1997; Wang et al. 2000). Matthews and Singh (2009) undertook a photovoice approach, which sought to promote understanding of the needs of African refugee young people while at the same time stimulating the development resources and pedagogies with a group who were struggling with the English language in the local high schools in Australia. In their Narrating Our World (NOW) project, visual methods enabled refugee young people to demonstrate their resilience, their enjoyment of their new lives, and their capacity to appropriate youth culture to their ends (Matthews and Singh 2009). The (NOW) Project trialed three forms of visual communication (Ramirez and Matthews 2008): digital photography, drawing and painting, and sand tray (that involved placing miniature figurines of people, animals, houses, water, bridges, fences, and so on, into a tray of sand to create stories and served as an interesting point of comparison with the other media). Photography was found to be the most productive in grasping the experience of refugee young people. Matthews and Singh also highlight that many young refugee people did not want to represent themselves in ethnic, cultural, or national terms. Neither were they interested in generating accounts of themselves as victims of inadequate educational and resettlement regimes. Thus, visual methods enabled refugee young people to demonstrate their resilience, their enjoyment of their new lives, and their capacity to appropriate youth culture to their ends.

In the similar vein, Oh (2012) found photovoice used in photo-friend program with Burman refugee children in Thailand as an alternative to research that pictures

children who have experienced war within the narrow framework of “victims.” Oh found a photovoice technique particularly useful in research with refugee children living in camps. She used photographs and photo-elicitation to glean information about the material circumstances of their everyday lives, as represented by them. The interpretation and analysis of the research did not center on the composition of the images. Instead, the key data came from the interviews and conversations with the children. The children’s narratives provided context and meaning, giving us a window into their social worlds and their interpretations of everyday life and their surroundings. Moreover, the technique induces an indirect way of gaining access to refugee children’s experiences of conflict, displacement, poverty, and food insecurity, thus reducing the possibility of causing them distress.

Photovoice works within photo-friends program, which engaged postsecondary students who receive training on research and interview skills and practice using digital cameras. These students were introduced to the boarding house children to pair students (aged between 18 and 23 years) with children who are either orphaned or separated from their parents for mentoring sessions so they could teach them how to use the cameras. The children are asked to take photographs of whatever strikes their fancy. They are then asked to choose and talk about the photographs, which are significant to them. An unstructured approach to the interview was used, where the children were encouraged to talk about their chosen pictures. The rest of the session included questions designed to elicit information about the children’s physical security, food, relationship with adults and peers, health, school, play, movement, work, and everyday activities. The program has run for four to six sessions with each child over a 2-month period (Oh 2012).

Oh evaluates photovoice in photo-friend program as being a subtle and sensitive tool that allows generating a rich, valid, and meaningful visual and textual representation in an indirect and unobtrusive way, thus reducing the likelihood of causing harm to children during the research. As she further argues, research about refugee children tends to focus on indicators of their nutrition, health, and schooling, rather than on their lived experience as a whole. For many of the children, photovoice was the first time that their thoughts and opinions were solicited by adults and incorporated into a project that would have an impact on their well-being. Thus, photovoice as used in photo-friends as an alternative to research that conceptualizes children who have experienced war within the narrow framework of “victims” (Oh 2012, p. 287). As such, this method has often been used to promote change in the lives of oppressed and disenfranchised groups, including refugees (Green and Kloos 2009; Oh 2011).

In the ultimate example, Marshall (2013) reports on the project, which conducted a variety of qualitative, visual research with small (about six children each) groups. Activities included guided tours of the camp, photo-diaries, participatory video projects, mental mapping, drawing, and focus group interviews. Marshall works with Palestinian refugee children aged 10–13 in the schools and community centers of Balata Refugee Camp. The project examined the ways in which Palestinian children variously perform and transform the discourse of trauma and the aesthetic of suffering that have come to dominate representations of Palestinian childhood and the Palestinian struggle in general. The data gathered demonstrates everyday beauty

in the lives of Palestinian refugee children, as found in mundane spaces and enacted through interpersonal relationships, constitutes an aesthetic disruption to the dominant representation of trauma as put forward by international humanitarian-aid organizations and development agencies (Marshall 2013, p. 57).

This funding resonates with Matthews and Singh (2009) who expected photographic images, artwork, and narrative accounts to deliver negative reports of traumatic presettlement experience, as well as the trials of postsettlement of young African refugees in Australia. Instead, they received images and accounts of full, busy, and happy postsettlement lives. Through the participatory activities, they also realized that participants were less concerned with communicating about the trials and tribulations of school, than in the opportunity to meet people with similar experiences and overcome their social isolation. Visual methods enable us to understand better the resilience born of the cultural and political conditions of refugee experience.

6 Conclusion and Future Directions

Two issues seem to be of particular importance when discussing migrant and refugee children participation in visual research: their representation and recognition. As Marshall (2013) points out, the notion of ethics as the distribution of what can be seen and heard and aesthetics as the disruption of the dominant distribution of the senses not only presents a challenge to conceptions of the political, but also challenges social science research itself, in particular research with children.

While attempting to balance adult-centered and child-centered methods, many research presented in this chapter, including my research with migrant children in Scotland, did not use these research method in isolation but for example combine visual child-centered methodologies with adult-centered research examining the production of children's discourses (Marshall 2013). In my research, migrant children drawings and maps clearly brought to my attention the children's ideas and concerns about their transnational experiences and practices (Moskal 2015). Visual methods were not used exclusively but were employed as supplementary methods to the narrative interview and observation in the family or/and school context to maximize opportunities for researchers to understand the children's experiences. The combination of methods also allowed researchers to be more conscious about the ways children expressed themselves with the visual methods (Liamputtong and Fernandez 2015; Kurban and Liamputtong 2017). The value of eliciting and analyzing visual methods is now well established and widely used in ethnographic research among adults (Prosser 1998; Pink 2001), although surprising little of it examines drawing. As the following overview makes evident, a growing number of researchers are taking seriously Wagner's (1999, p. 4) suggestion that "placing images in the foreground of our talk with children can increase opportunities for getting a clearer sense of what kids think." I found that asking children to draw a picture or a map related to the topic and then to tell a story to go with this is a good strategy to facilitate an interview. Particularly, a standard, lengthy series of questions and answers may not work as well for children as for adults. My research in the

Scotland provides evidence of the value of using drawing and mental maps accompanied by interviews as a research strategy among migrant children.

Visual research methods have frequently been discussed as not only suitable for a child-oriented research process, but even more so for research with children and young people with limited language skills or who may have complex experiences of trauma (see Young and Barrett 2001; Crivello et al. 2009; Due et al. 2014; Liamputtong and Fernandez 2015; Kurban and Liamputtong 2017). In working with refugee and asylum children and young people, commonly used approaches include a photovoice (Matthews and Singh 2009), photo-friend (Oh 2012), photo-diaries, and participatory video projects (Marshall 2013), or mapping exercises (Gifford and Sampson 2010; Kurban and Liamputtong 2017), to mention a few examples. Over the years, some concern has been raised if these approaches are to be more widely adopted. The requirement for anonymity usually prohibits publication or public display – for example, on the project websites – of images (photographs/photo-collages/videos) produced by and depicting participants. Thus, the research participants (refugee young people) might not receive the recognition they initially desired (Matthews and Singh 2009, pp. 64–65). It is an argument against reaction that assumes that anonymity is always desirable. Anonymity can act to silence as well as to protect. Smudging or pixelation of images is the visual equivalent of anonymizing text (Lodge 2009). The anonymizing of images reinforces, in fact, the invisibility of research participants and vanish their efforts to locate themselves as creative agents and active research subjects. While research project could give young people access to technologies and other resources, which enabled them to represent and subvert negative images and narratives of themselves and their families, the strictures of research ethics concerning anonymity meant that the project limited participant's capacity to challenge dominant victim-orientated narratives of refugees (Matthews and Singh 2009).

Some scholars have pointed out that the discourse on and conceptualization of refugee children (Hart and Tyrer 2006) is often framed around their vulnerability, helplessness, and role as victims. Conventional wisdom on research methods with children also highlights their vulnerability to persuasion, adverse influence, and harm in research, as in the rest of life. Many research, however, demonstrate the visual participatory method can elucidate children's understanding of their everyday experiences and allow young people to express themselves.

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Participatory and Visual Research with Roma Youth

100

Oana Marcu

Contents

1	Introduction: Ethical Research with Migrant and Ethnic Minority Groups	1740
2	Participatory Action Research with Youth	1741
3	Visual Research with Marginalized Youth	1742
4	Methods and Instruments in PAR with Youth: Two Examples	1744
4.1	Roma Youth and Drug Use: How to Design Visual and Participatory Research ...	1744
4.2	Peer Research on Migration, Gender Scripts and Cultural Change	1748
5	Conclusion and Future Directions	1752
	References	1753

Abstract

Drawing from two examples of research carried out with Roma youth, this chapter discusses applications of participatory research, backed up with visual methods and creative group techniques. It describes methods, tools, and strategies which can be used in peer-research with young people belonging to minorities, from migrant backgrounds or marginalized ethnic groups. In the context of ongoing political debate regarding the minority status and migration rights of the Roma in all European countries, knowledge construction processes are particularly sensitive to issues of age, class, gender, and ethnicity, intersecting in transnational processes. The lack of self-representation of the Roma in the public sphere, as a group discriminated against on an ethnic basis, leaves a need for participation in knowledge-making processes, and research can contribute in this direction. While participation addresses some ethical issues in cross-cultural research, by leaving space for participants' perspectives, it also means having to address competence, class, and power distances that may exist between the researcher and the participants. This goal invites the researchers to use new

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1739

tools in order to engage young people in creative and reflective explorations. Research strategies such as the participatory design process and choosing specific levels of participation in all stages are discussed. Visual and participatory methods are illustrated here with examples from two research projects: the first one on the representation of drugs and the second one on the migratory experience from a gendered perspective.

Keywords

Participatory action research · Visual research · Peer research · Migrant and ethnic minority groups · Youth

1 Introduction: Ethical Research with Migrant and Ethnic Minority Groups

When conducting research with migrant and ethnic minority (MEM) groups, researchers need to consider the ethics of ethnic data collection and the management of power gaps, to work in the group's best interest without increasing stigma. When social change is also a goal, effective action and reflection cycles should be backed up by the necessary authority and power to improve the condition of the group we are interested in. These are typical issues that have been put at the center of the Participatory Action Research (PAR) approach, which I will briefly present below, focusing on its educational and empowerment potential in working with young people.

I refer in this chapter to the Roma as a migrant and ethnic minority group, present mostly throughout Europe, but also on other continents (Piasere 2004). The situation of the Roma can reveal exclusion patterns and identity construction processes shared with other MEM groups, and can be taken, contextual factors ascertained, as a case study for the condition of many minority groups.

Different Roma groups are present in most European countries, with different legal statuses, cultural, linguistic, and historical backgrounds (Piasere 2004). In Western European countries, they have been traditionally associated to nomadism (Piasere 2004). Within Europe, some groups are recognized as national minorities, while others are citizens with no official recognition. Others still are migrants, EU citizens, or third-country citizens. Local groups tend to identify themselves as culturally different from one another (Marcu 2014). Piasere (2004) points out that "Roma" is a politethical category, meaning that its members have some similar traits, but without a common core of traits that could define this belonging.

This is one of the reasons why talking about "Roma health" can be a misnomer, as the different ways in which we interpret ethnicity and define this group lead to quite different lines of research and intervention (Matras 2016).

Researchers need to pay special attention to those determinants of health that particularly work against stereotypical interpretations of difference, pointing out how inequalities weigh on marginalized groups, often as a result of institutional and structural discrimination. Such determinants might include legal status,

differential rights, and barriers in access to health, inadequate welfare support, poor living conditions, homelessness and substandard housing, informal, precarious and unstable work, stress connected to poverty, and fear of discrimination and of xenophobic violence.

The risk of essentializing culture and using it to explain behaviors can have negative consequences for the group, at the level of public opinion and policy-making. Accepting and reinforcing reified definitions of “culture” and “ethnicity” gives them facticity outside of the human and social processes that create them (Berger and Luckmann 1966). If we do not examine their genealogy and their processuality (Baumann 1999) and, thus, assume that the typical characteristics of the group uniformly apply to all members, we can give rise to even stronger, and apparently “evidence-based,” racisms. This risk can increase when findings are interpreted as ethnic differences, without accounting for the processes that construct them.

Qualitative research methods and, even more, participatory methods, allow us to connect health behaviors and challenges to the meaning attributed to them and to the more general social context, from the point of view of those who can best describe and reflect on their own experience (Higginbottom and Liamputtong 2015; see also ► Chaps. 63, “Mind Maps in Qualitative Research,” and ► 17, “Community-Based Participatory Action Research”). Health behaviors, just as cultural consumption or gender norms, express a dynamic process of relating to the “other” and to one’s own stigmatized position and can thus reveal good indications for shared, responsible, and respectful social intervention.

2 Participatory Action Research with Youth

Participatory action research is a process in which research, education, and action are intertwined, as participants take an active role in addressing issues affecting themselves, their families, and their communities, with the goal of producing social change and empowerment (Brydon-Miller 2001; Higginbottom and Liamputtong 2015). It has very often involved groups that have been exploited or oppressed (Brydon-Miller 2001).

Participatory action research is connected to two main ideals: emancipation and empowerment (Boog 2003; Higginbottom and Liamputtong 2015). Emancipation refers to contesting the distribution of power in the society and to transforming it in order to reach a more balanced state, and is inspired by critical theory and Marxist approaches. Empowerment was initially connected to developing self-consciousness, self-actualization, and self-advocacy, at a more individual level. It is connected to the development of the capacity to solve problems while generating critical knowledge of the system in which the problems exist (Boog 2003). Both researcher and participants are more actively involved in the process than in traditional social research, as they share responsibility for a process whose impact does not rely on the insufficient feedback loops that exist between mere academic knowledge production and social change (Higginbottom and Liamputtong 2015).

PAR projects may range from institutionally funded social research and intervention (as is the case with both of our examples presented below), to classroom educational methods (Kennedy 1989; May 1993), and to academic activism (Chatterton et al. 2007). Critiques of participatory methods argue that they are not always capable of generating equality and empowerment (Cooke and Kothari (2001); using participatory techniques in otherwise researcher-driven processes can be misleading, and surely does not achieve full democratic participation or social change (Pain and Francis 2003). Instead, various authors have discussed a participation continuum, ranging from co-option to collective action (De Negri et al. 1999; Arnstein 2004; Kindon et al. 2007; Higginbottom and Liamputtong 2015; see also ► Chap. 17, “Community-Based Participatory Action Research”).

More specifically, PAR with youth, which I will refer to also with the term peer-research, works on the inequality axis of age, aiming to give young people more freedom of expression and involvement in the relevant decisions for their lives (Nairn and Smith 2003). Just like in other forms of participatory research, involvement in all research stages, from the design to the dissemination of results, is crucial in order to produce empowerment or social change (Nairn and Smith 2003; Conrad et al. 2015). Kennedy (1989), in an early attempt to use peer-research, underlines the educational value of this approach, but remains skeptical regarding the value and validity of the knowledge produced by young people carrying out research.

Price and Hawkins (2002) use peer ethnography in order to conduct research on sexual and reproductive health, starting from the assumptions that it is easier to establish the trust relationships needed to approach intimate topics between peers. From this point of view, peer research uses the insider role of young people in their own networks to allow for a stronger involvement of the community in the research process. However, the authors realize that peer relationships are not always characterized by consensus, but also by conflict and mistrust. Thus, their insider status is not always of help in data collection (Price and Hawkins 2002).

Peer research is connected to peer education, which is based on a natural way of learning and education, established between young people sharing the same life context and networks, bringing educational intervention closer to the communities (Youth Peer Education Network 2005).

3 Visual Research with Marginalized Youth

Although not directly connected to the history of PAR, visual studies initiated their own research experiments aiming for social change. Various assumptions are at the core of these research methods. These include: the power of self-representation in challenging established discriminatory practices and worldviews, the potential of visual messages to reach larger, targeted, and more engaged audiences, the possibility of producing change by decolonizing communication processes (Frisina 2013).

These assumptions find fertile ground in social research, in particular with marginalized groups, in order to reach various goals. First, images are used to enrich social research, by exploiting their specific qualities, as they are polysemic, vivid, metaphorical (Gauntlett 2007; Grady 2008). Paying attention to the visual material culture also means the recognition of popular culture as legitimate for academic interest, an idea pioneered by the cultural studies school (Frisina 2013).

Second, visual methods facilitate the engagement of young people by enriching the possible means of expression, allowing them to spend more time with the questions and ideas stemming from research topics (Gauntlett 2007). This contributes to in-depth and sensitive social research. As a consequence of engaging in the process and gaining more expressive competence, the potential of visual methods to bring about transformative effects, typical of PAR, grows. This is the case for the **photovoice** method, considered to be a PAR method, which consists of asking participants to shoot photos on an important topic for their everyday life, to comment and discuss them and then to present them to a relevant audience (Wang and Burris 1997; see also ► Chaps. 65, “Understanding Health Through a Different Lens: Photovoice Method,” and ► 99, “Visual Methods in Research with Migrant and Refugee Children and Young People”).

Third, images are useful to disseminate better and to talk to wider audiences, supporting the diffusion of counter-narratives and enhancing the impact of research and action.

Due to their metaphorical and artistic potential, their role in generating reflective thought is also not to be ignored. This introduces a new, aesthetic dimension in the knowledge production process that is also related to the effectiveness of the dissemination and, thus, to the impact of visual research. An aesthetically and communicatively efficient product might need the involvement of experts or artists that can support the creation of vivid representations and transmit the competencies needed to use techniques and media. The balance between the input of experts or artists and the input of peer participants is negotiated in each step, but financier’s standards, time, and resources have a large impact (Bugli, personal communication, July 13, 2016).

In research-oriented visual production, the subjectivity of the image reflects the relationship established between researcher and participants. When we involve artists and experts, we introduce “forms of polyphonic authorship” (Frisina 2013, p. 11) in the process and imagine a wider audience for the products.

The **participatory video** is a process where the complexity of the medium does require different professionals to be involved, starting with the producer/director, who, in this case, should put him or herself in the position to tell other people’s story, not to create his original story, as is common in artistic production (Seidl 2003). With this method, researchers involve grassroots stakeholders in producing video messages as tools for self-definition, empowerment, education, community building, and activism (White 2003).

Visual methods can, therefore, strongly contribute to PAR by supporting wider participation of those excluded from the academic and public writing processes, and reaching wider audiences for research products.

4 Methods and Instruments in PAR with Youth: Two Examples

In any qualitative research design, most of the planning is creative, but in PAR it should be even more flexible because decisions are not taken by an expert researcher alone. Similarly, methods and instruments to be used have to be easily managed by people who do not have extensive training in social sciences.

The flexibility and interdisciplinarity of PAR link it to a more artisan style of planning, and PAR facilitators, often professionals in the educational field, have included pretty much everything that could have a transformative and engaging potential in the process: arts and theater, music, video, live performance, and so on. These methods can actually be combined in many ways, when the researchers allow themselves to be guided by the resources and interests of the people involved. I will show and discuss, with two examples, how my team and I organized the PAR processes and the decisions we took in various steps, in order to make the most of each situation.

The first example focuses on three key elements, from a methodological point of view: involving stakeholders in designing the research, using the visual instrument of the collage, and applying metaphorical analysis. With the second example, I will present various research and action methods used with Roma young people (theater, photovoice, interviews, participant observation, focus group) along with some instruments (concept maps, collage, decision-making techniques) in order to creatively facilitate the work with youth with only basic literacy skills.

4.1 Roma Youth and Drug Use: How to Design Visual and Participatory Research

“Addiction Prevention Within Roma and Sinti” (SRAP), was a 3-year project, financed by the Executive Agency for Health and Consumers of the European Union, comprising research, training, and piloting of addiction prevention interventions with Roma youth, in six countries. The consortium, made up of institutions responsible for providing social and health services, research bodies, and NGOs working in the field of education and health, carried out the activities in a coordinated manner, transnationally. The research was conducted in the first project year and managed by a central team composed of myself and two colleagues from Codici Research and Intervention, a private firm active in research and consultancy based in Milan (I will use the first-person plural to refer to the collective work done by the scientific coordination and the local teams forming the consortium.) (Marcu 2015).

Little was known about the topic, as few surveys have explored indicators of drug use among the Roma. Results were quite alarming because of the significant differences in the incidence and level of use, abuse, and addiction, when compared with the general population. Previous research identified tendencies such as early ages for the onset of tobacco and alcohol consumption, diffuse problematic alcohol consumption, wide use of self-medication with tranquilizers, sleeping pills and relaxants, higher lifetime prevalence for all types of drugs, and stigma and concealment of consumption (EMCDDA 2002, 2008; Fundación Secretariado Gitano 2009). Most scholars attributed the wide health disparities between the Roma and the general population to the conditions of poverty in which most members of this ethnic group live (Földes and Covaci 2011) and on the barriers that this group meets in access to appropriate health care (Ivanov 2004).

Drug use and addiction was perceived as a problem also among the professionals that were involved in the project. In order to test this hypothesis with young people themselves, and to get better guidance regarding the priorities, from their point of view, we needed to involve them from the research design phase.

The **participatory design process** (Bergold and Thomas 2012) is a strategy that aims to overcome a common limitation: that research design is usually decided by experts (most of the time in the phase of the financing application) and remains the stage which participants control the least, although it is the stage with the biggest impact on the research (Nairn and Smith 2003).

Building the research design together with the target groups helped us understand how to approach the drug “issue” in a nonstigmatizing manner, working with parents’ and young people’s existing interest and motivation to tackle this problem in their communities.

For this planning stage, Roma youth (74 participants), decision-makers in institutions or NGOs (41 participants), and professionals in the field of addiction and social work with Roma (62 participants) gave their contribution in 23 group meetings, with the specific goal of offering indications for the research design regarding targets, contexts, recruitment, and ethical issues. The procedure of these meetings consisted of a brainstorming task on the topic “Roma youth and drugs,” followed by the instigation of a concept map.

Concept maps are graphical tools for organizing knowledge, for meaningful learning, and can be used as group facilitation tools. As Novak and Cañas (2006, p. 1) explain, “they include concepts, usually enclosed in circles or boxes of some type, and relationships between concepts indicated by a connecting line linking two concepts.” The main categories of concepts were then ranked by participants on the basis of their importance and of their accessibility for research and prevention actions. They then prioritized the problems, ordered the resources, identified the critical issues, and warned about potential errors to be avoided in the research process.

The results of these meetings contributed to the development of a conceptual framework that guided the construction of tools for data collection and analysis. Results were summarized transnationally in a group process with professionals that had facilitated the local meetings.

The data collection and the analysis of the results were then carried out by the same professionals (outreach, educational, and social workers) with the help of Roma mediators. They were trained in research methodology and in the use of the specific tools designed for this study by the scientific coordination team. As a part of this transnational coordination process, my team and I conducted shadowing and onsite training of field researchers, facilitated constant exchange between them, periodically summarized results and observations, reviewed the instruments after the pilot study, and gave feedback on the results.

Surely, in this research, the voices of social workers and mediators, who had a more constant role in all stages, were stronger than those of the young people and other stakeholders involved in the design.

Following this preparatory stage, the local teams conducted 23 visual focus groups and 58 life-story interviews in all countries, with 199 young Roma, out of which 98 were aged 11–13, while 101 were 14–16 years old.

The **visual focus groups** used the technique of the **collage**, a less common method, recommended by some positive experiences (Awan 2007; Reavey 2011). It involved participants in the process of pasting various materials on a white sheet of paper, such as newspaper clippings or parts of photographs, around the topic of their relationship with alcohol, tobacco, and other drugs. Researchers interacted with participants during and after the execution of this task, eliciting meanings involved in the choice and placement of the images. Following the production and presentation of the collages, the researcher guided a group discussion about the shared themes, in order to reach an understanding of the issues with input from all participants, interacting with one another (Fig. 1).

The **elicitation**, usually conducted with photos, here with collages, helps researchers gain more insight into participants' points of view, by relying on the verbalization of intended meanings. This process, as Harper (2000, p. 725) suggests, can be seen as an insight into cultural explanations, a "cultural Rorschach test."

It is common to use print media (such as magazines and newspapers) for the collage task, but it is important to acknowledge that it can introduce bias in the direction of socially accepted or commercially promoted images and discourses. As concerns minority groups, media communication has often been found to misrepresent and to stereotype negatively; or the lack of depiction of these groups in the media constructs by omission their social identity as marginal. There have not been many studies regarding the representation of the Roma in the media, although a few examples pointed out negative, stereotypical discourse. Also notable is the lack of representation and absence of the voices of Roma and Sinti: they are pictured by the voices of others (Waringo 2005; Sigona 2006).

Visual focus groups were backed-up with individual life-story interviews with conducted with the older youths (17–24 years old), who were purposely selected as consumers of different drugs, 37 male and 21 female. Given the focus of this chapter on visual methods, I will not detail the interviews, a more traditional way of gathering data, which followed the nondirective approach proposed by Bichi (2002).

The interpretation of the data put participants' motivations, interests, and perspectives, subjectively raised during the interviews, at the center of the



Fig. 1 Collage produced by participant in Madrid, Spain, divided in three sections corresponding to alcohol, tobacco, and other drugs

explanations. With visual materials, we used **metaphorical analysis** (Schmitt 2005), drawing on the seminal work of Lakoff and Johnson (1980), who argue that social thought, language, and action processes can be understood when studying individual metaphorical models and collective ones. We used the steps proposed by Gauntlett (2007): listed the signifier and the signified for each metaphor, identified recurrences, similarities, contrasts or other relationships between metaphors, then mapped source and target domains in order to access broader areas of meaning. In later stages, it was possible to link metaphors by means of interpretation, to categorical knowledge and to the initial conceptual areas. Some participants wrote texts in the collage, ranging from just a few words to page-long stories, next to images which were also used as an input for analysis.

Other sources of interpretation were the image composition, disposition, closeness, relative dimensions of the components, and types of elements (persons, objects, and their characteristics), following the argument made by Bohnsack (2008) regarding the analysis of the formal structure of images. In this manner, it is possible to reconstruct preiconographic knowledge that is difficult for participants to conceptualize or verbalize.

One of the most interesting findings of this research was describing meanings that linked health behaviors to the construction of ethnic, class, and gender identities. The use of particular types of drugs expressed identification with a nonethnicized peer group and culture, and were linked to social change within the younger generation of Roma, while other drugs are seen as “drugs of the poor,” their use was explained as a

reaction to continuous stress related to poverty and to the marginal status. Girls' consumption had different patterns than boys' and was more stigmatized. The rich meanings produced using these research methods produced evidence that drug consumption is connected to the negotiations between keeping tradition and being part of a globalized youth culture.

With this research example, I intended to show how the participation of various stakeholders, especially of youth, can be central in the initial phases of the research, even if, given the transnational dimension and the resources constraints, it could not be implemented in all phases. Although this does not ensure the creation of a profoundly democratic knowledge-making process, it sets up a good level of collaboration with young people, strengthening the representation of their own perspectives, as compared to traditional social research, where they are involved only as respondents. Other stakeholders (specifically, professionals in social work) had the central role in training, in data collection and data analysis, while my team of expert researchers kept control of the entire process, consulting and collaborating with the partners at each step.

4.2 Peer Research on Migration, Gender Scripts and Cultural Change

The second example I will discuss involved only Romanian Roma in Italy, and focused on their experiences regarding their migrant condition. It was part of a series of projects dealing with irregular Romanian Roma's migration, especially that of young people involved in street work (begging, playing music, or doing petty crime). The projects followed an action research approach, relying mainly on street and institutional ethnography, but also on biographical interviews, peer-research, and group work with social services and NGO professionals (Marcu 2014). It was conducted by a team from Codici Research and Intervention including myself, and two colleagues, and coordinated by a senior researcher.

Romanian Roma's migrant condition is characterized by extreme precariousness: undocumented work, precarious housing conditions ranging from abandoned buildings, tents, or shacks to authorized encampments, and (very seldom) social housing or rented apartments. Young Roma coming to Italy are involved, especially initially, in street work, with all the other members of the family. When supported by volunteering organizations or social services, however, they tend to reach higher school levels than their parents and successfully follow job integration programs (Fondazione Casa della Carità 2012; Marcu and Bacigalupo 2013). Migration, therefore, brings many changes in young people's lives, and with their participation in nonsegregated street, school, and work environments, intergenerational gaps grow wider.

Within this context, the peer-research was intended to create better knowledge regarding the meaning that young Romanian Roma attribute to their migratory experience, while developing empowerment and giving them a public voice, using expressive means familiar to them, put in the context of systematic, participatory social research. Seven young people aged 15–18 participated in the process, which

was framed as a research scholarship, accompanied by three facilitators with different expertise (social research, educational work, photography) and two undergraduate students working as interns. I will use the first person plural to refer to the more expert research group, formed by the three facilitators and interns. The peer-research involved various other experts, such as a DJ, an actor, and an ethno-psychologist, who supervised the entire process.

The participants were chosen using the snowball sampling method, with the mediation of outreach workers from local organizations that worked on the transition from being vulnerably housed to more stable housing and from undocumented work to official employment. This was done in order to find volunteers with more stable life conditions than those we met in street ethnography, as the request of sustained participation excluded those living in the harshest conditions. We also asked that participants have at least basic literacy skills. All the volunteers ensured us of their interest, motivated by the topic, which was relevant to their life experience, but also by the financial reward. In the end, we did not operate any selection, but covered the available places as people applied and accepted our offer.

The first phase of a **theater laboratory** involved a professional actor who trained the group on self-expression, self-presentation, group cohesion, and trust (Fig. 2). Divided in two smaller groups, participants prepared two stories, freely chosen, interpreted only using gestures, facial expressions, objects, space, and movement. The first group represented a love and migration narrative, in which a young girl wins a scholarship to study abroad where she falls in love and lives her story freely. The second group represented a story that was quite close to their own migratory experience, comprising migration forced by poverty, ending up begging and squatting.



Fig. 2 Peer researchers and facilitators during the theater laboratory (Photography: Luca Meola)

The next instrument we used in order to explore participants' stories was the **collage**. Each participant represented his/her past, present, and future identity. I described this instrument in the previous example, and here we followed a similar procedure. The initial stories and the collages produced a wealth of material on young Roma's migratory experiences which we grouped and analyzed by building together a **concept map** (as described above) around the central topic of "Young Romanian Roma in Migration." In order to choose just one topic on which to focus in-depth in the following stages, we used an adaptation of a well-known decision-making technique, the **Six Thinking Hats** (De Bono 2000). We asked participants to rate the main themes of the concept map, taking into consideration how much they liked the topic, how emotionally connected they felt to it, the capacity it had to represent young Roma life, and the interest it presented to the general public. The topic of romantic relationships was chosen, confirming the importance of the affective sphere in young people's life.

With this choice, the process we initiated was adopted in an intergenerational and cultural protest/negotiation, thus becoming more than just a knowledge-making process: a ground for young people to express their freedom of choice as well as their belonging.

With this topic, facilitators proposed that an in-depth exploration of the perspective of Romanian Roma could be conducted.

The **research design** was unfortunately proposed as an abstract and academic scheme. What seemed like a natural task to expert researchers proved to be boring and frustrating for young participants, leading to the goals of this phase not being achieved.

This generated a discussion on the choice of the groups to be interviewed in research. In a research-oriented approach, bearing in mind the ideal of triangulation, facilitators suggested that various stakeholders were interviewed, including the parents. Participants strongly resisted, as they wanted to voice their own experiences, and would not accept hearing others, more powerful than themselves, on such a sensitive topic. We finally agreed with peer-researchers to interview only young people, single or couples, and to include both endogamous and mixed couples.

The following step was exploring their everyday life, by means of a **photovoice** process (applied as described above). Participants took photographs of their life settings, focusing on the general context rather than specifically on romantic relationships, which we considered a sensitive topic to explore with this medium, for privacy reasons, as some participants were minors. They represented living conditions, relationships between peers, and friendship, chose five photos each to be presented to the group, and were interviewed by the group on the content and intended meanings (Fig. 3).

Then we passed on to **interviews** with other peers, specifically on the topic of romantic relationships in youth and adolescence. The group built an interview guide eliciting stories of various stages of "love," also asking about relationships with parents and their opinion and reaction to the love story being recounted. The peer-researchers were **trained with simulations** for in-depth interviewing as they tested the guidelines within the group of peer-researchers, and received feedback on their questioning and listening skills. They then conducted 25 interviews, in our office or in the places where they lived, with young people they knew more or less: friends, neighbors, schoolmates.

Fig. 3 Photo produced by during the photovoice process by one of the peer-researchers around the topic of the living conditions of migrant Roma in Italy



The interviewed persons were chosen by convenience sampling and snowball sampling, all were Romanian Roma aged 14–25, 4 girls and 21 boys.

The context where the interviews were carried out greatly influenced the content and constituted a topic for further reflection. We backed up the interviews with participant observation, but instead of having peer-researchers write fieldnotes, we discussed them in the group meetings, which were documented by the two interns. When interviews were carried out in camps or squats, there was no privacy, and they became informal conversations mostly among young men, comprising socially accepted versions of gender and sexuality scripts. In more private spaces, such as in family shacks or in parks, it was possible to gather more personal experiences.

Another issue concerned the relationship of trust between interviewers and interviewees. We assumed that it would have been easier to talk about intimate relationships between peers, but the thick network of power relationships in young people's living contexts leads to differential levels of trust, even among those who share the same age. The small number of girls that agreed to be interviewed is an indicator of this, as the consequences of revealing the intimate details of their romantic relationships can be devastating for their reputation. A solution to this drawback is to use indirect, third-person questions or projective questioning techniques (Price and Hawkings 2002; Bichi 2007).

Aware of the role that Romanian Roma music genre *manele* plays in young people's lives, we invited participants to summarize the results of this research by telling the story with a **music compilation**. They selected the songs and prepared a mix, with the support of a professional DJ.

For a more formal **analysis of the results**, we used a **focus group** format, relying on interactional dynamics, generated by the stimuli that the team of facilitators: transcribed interviews, selected excerpts, photos, collages, the concept map, and the music mix. The intense discussion allowed us to record multiple positions and perspectives, which were presented to social workers, project partners, and the commissioning foundation. Facilitators also prepared an online blog, gathering all the materials produced above (except for interviews, which were summarized into anonymous stories).

Results pointed out that gender and sexuality norms for migrant groups, especially for youth, express a complex negotiation between tradition and change and have a crucial role for ethnic identities. Many migrant groups affirm positive cultural identity through the reinforcement of traditional rules regarding gender and sexuality (Das Gupta 1997; Espiritu 2001). At the same time, young people challenge these norms, grow feelings of belonging to more than one culture and enact different ways of growing up, parallel to the traditional model. We assisted these complex negotiations in the areas of consumption, body display, and dress code, in cultural and goods consumption (Conte et al. 2009) and also with drugs, as shown above. In the area of gender and sexuality, young people talked about everyday battles. For example, they claimed the freedom to choose their spouse, criticizing arranged marriages and sometimes using elopements to force parents' acceptance, or the freedom to use birth control methods, in spite of the elders' family planning projects.

With this example, I intended to present a wider variety of methods and tools that can be used in order to engage young people in knowledge-making processes and, at the same time, to give an example of a peer-research where young people were involved in all research stages. The empowerment process was generated by numerous opportunities for self-reflection and expression designed to work on personal and group experiences, and polyphonic authorship was present throughout the process. Even if expert researchers maintained control and designed the entire research, at moments peer-researchers took control and claimed some decisions as their own.

5 Conclusion and Future Directions

Participatory action research with young people can be a fruitful option for knowledge production and a tool for education, empowerment, and activism, working on multiple axes of difference: age, class, gender, and ethnicity. Both examples I analyzed show a capacity to shed light on complex identity and behavior processes, starting from personal stories and working intensely with group interaction and reflexive tools.

The wealth of methods and instruments that can be creatively combined in PAR should take into account the capacities and resources of the people involved, the constant attention to authorship and direction, and the potential for engagement and reflexivity. Visual methods have a privileged position from this point of view, given the decolonizing potential of visual counter-narratives.

The two examples present different levels of participation of the target groups in the research process, and are both ascribable to PAR. The first one is closer to consultation, as young people gave precious advice regarding the research design, while the second one, closer to co-learning, with young people engaging in knowledge sharing and generating communicative action with our facilitation (De Negri et al. 1999). If we want research to be scientifically recognized while completely sharing decisions and tasks with participants, we find ourselves teaching some competencies that are far from young people's daily experiences and difficult to recycle in other areas of their activity (research design, data analysis). It, therefore, makes sense to diversify roles and tasks while reducing the level of their involvement in more abstract tasks, or in tasks that are not interesting to them. It is valuable though to clearly identify the levels of participation, authorship, and direction in the various phases of PAR research.

While more horizontal and engaged participation of young people in research and social change should remain one of the main goals of scholars working with marginalized youth, problem-specific engagement and consultation practices can still improve the collaboration between researchers, practitioners, and young people.

PAR with marginalized youth is highly engaging for the expert researchers too. Overlapping roles as scholars, facilitators, employers, and friends can create confusion and might require the high emotional involvement typical of long-term, ethnographic work. Documenting this process with personal fieldnotes can be useful for greater reflexivity and interaction with youth.

Visual communication and the bottom-up creation of visual culture is ever more present today, thanks to the new media, and young people have the possibility and capacity to express their minds and fight their struggles using these tools. Still, the access to the public sphere remains uneven, especially if we keep in mind members of the migrant and ethnic minority groups. PAR can give its contribution to filling up this gap by bringing in support, expertise, resources, as well as drawing from its ability to question the taken for granted and deconstruct hegemonic narratives that are detrimental to migrant and ethnic minority groups.

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Drawing Method and Infant Feeding Practices Among Refugee Women

101

June Joseph, Pranee Liamputtong, and Wendy Brodribb

Contents

1	Introduction	1758
2	Situating Ourselves	1758
3	The First Author's Personal Encounter with the Drawing Methodology	1759
4	The Postmodern Turn: The Use of Drawing Among Vulnerable Populations	1761
5	The Drawing Method	1761
6	Drawing in the Context of Participants from Refugee Backgrounds	1762
7	The Real-World Application of Drawing in Our Research	1763
7.1	Participant: <i>"I Am Sorry, I Cannot Draw"</i>	1763
7.2	Research Team: <i>"That Is Okay. . . It Must Be Hard for You. . . Let's Move On. . . Now This an Interesting and Brilliant Concept. . . Would You Like to Sketch It for Me."</i>	1765
7.3	Participant: <i>"This really unleashes my past. . . I have never seen myself capable"</i>	1766
8	The Refugee Perspectives of Infant Feeding	1768
9	What Women Use Drawing For	1768
9.1	To Illustrate a Location	1768
9.2	To Illustrate the Concepts of Motherhood	1769
9.3	To Illustrate Vulnerability	1770
9.4	To Illustrate How Mothers Counter the State of Vulnerability	1771
9.5	To Illustrate the Freedom in Australia	1771
9.6	To Illustrate the Goodness of Breast Milk	1772
10	Conclusion and Future Directions	1772
	References	1773

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1757

Abstract

The pressures exerted by political agendas in third world nations continue to displace many individuals daily, with mothers being greatly impacted due to their dual child-bearing and child-rearing roles. Mothers arriving in a new Western country are confronted with a need to adapt into a new societal norm and healthcare system. This “shift” frequently impedes their ability to breastfeed optimally due to the clashing belief systems. Often, mothers are judged and discriminated for the way they choose to “mother” their infants. Their cultural beliefs and perspectives of infant feeding, compounded by the stressful trail of resettlement, are unknown to authorities in Western nations due to their silent unassertive nature. This chapter uses the postmodern methodological framework to unravel the multiple truths that drive the perceptions and perspectives of infant feeding among Myanmar and Vietnamese mothers from refugee backgrounds in Brisbane. Since the research trend of gaining visual access to the lives of mothers from refugee backgrounds is new, we also outline some tips and tricks that steered our initially rocky data collection journey. The chapter continues with ways in which women from refugee backgrounds conceptualize motherhood and infant feeding. Finally, we delineate the implications for practice and the usefulness of using drawing as research method for practitioners who work around this scope.

Keywords

Drawing methods · Refugee · Mothers · Breastfeeding · Infant feeding · Displacement

1 Introduction

Arts-based research has been gaining popularity in qualitative social and health research (see ► [Chap. 64, “Creative Insight Method Through Arts-Based Research”](#)). Bergum and Godkin (2008) contend that the application of art in research processes could cover a wide spectrum of areas namely where it can be used as an inspiration, method, intervention, data, or as a mode of dissemination too. This chapter focusses on the use of arts-based research with particular attention to drawing methodology as a means of gathering data to grasp the thematic essence of experiences (Van Manen 1997). An increasing number of social researchers (Broadbent et al. 2004; Cross et al. 2006; Fernandes et al. 2014; Gill and Liamputtong 2014; Guillemin 2004; Vitoria and Knauth 2001) have used drawing as a method of eliciting data and have found it to yield rich and meaningful information.

2 Situating Ourselves

This chapter is based on the work of June Joseph, the first author who is in her final year of a PhD that focuses on the experiences of infant feeding among refugee women. The study was supervised by Pranee Liamputtong and Wendy Brodribb.

With the suggestion and encouragement of Pranee Liamputtong, whom June asked to be her external supervisor, the exploration of drawings as research method/tool began three years ago. June's PhD research focusses on understanding the lived experiences of infant feeding and its connection with motherhood among women from Asian refugee backgrounds in Australia. The research incorporated mothers from two countries of origin namely Vietnam and Myanmar. These women have endured *journeys* of oppression, persecution, scarcity of resources, and disconnection from familiar support networks. June is not a refugee, neither is she a mother. Borrowing the concept of sociological imagination which echoes the connection between personal trouble and public concerns (Mills 2000), her interest in this research surfaced from an inner desire to understand how her late mother whom she conceptualize lived a "refugee" lifestyle managed her infant feeding days. In attempt to gain an extensive understanding of how women from refugee backgrounds theorize their infant feeding experiences, beyond the common notions available in published journals and medical textbooks, her research challenge was to dig deeper into other ways of "knowing" and engaging women of refugee backgrounds. As her late mother relayed her experiences in verbal and written forms, June desired an emergence of new concepts that visual art methodologies could entail – since the richness of subjective experiences that could emanate from drawing is currently a trend of discussion in the qualitative research paradigm (Knowles and Cole 2008). Her PhD research aims to engage mothers and to have them share their perceptions and experiences of motherhood and infant feeding visually through drawings as they narrate their stories. However, inasmuch as infant feeding is ingrained within generational belief systems, mothers communicated their entire childbirth experience – which explains why the perspectives of childbirth will also be covered in later sections.

Despite being inspired and enthusiastic about the richness of data that could be unraveled from the use of drawing as research methodology, almost all initial attempts we struggled to obtain artwork from the participants. After several "trial and error" attempts, the process of gaining insightful visual data became easier with time. Since the trend of forced migration is escalating, we believe that it would be priceless to publish the journey, tips and tricks of working with women from refugee backgrounds. We will commence the chapter with June's personal encounter with art.

3 The First Author's Personal Encounter with the Drawing Methodology

It is not uncommon for anyone, when subjected with a request to produce an artwork, to question their ability to draw and later deny it – with exception to children who willingly uptake the challenge. Somewhere along the growth curve, June had become conscious of judgments and the sense of unworthiness. Despite having been heavily immersed in various published reading materials, steered by the notion of *sociological imagination*, June knew she had to equip herself with the experience of

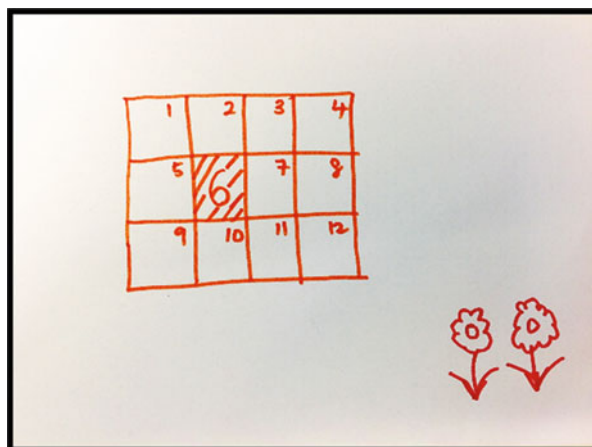
being subjected to drawing in order to successfully implement it in a research endeavor. Prior to embarking on the fieldwork, she was privileged to attend a workshop conducted by the mother of the drawing methodology herself, Marilys Guillemín in April 2015.

As enthusiastic as the delegates were, interestingly, it was dramatically short-lived. They were filled with shivers as they took their seats as they stumbled upon a sheet of paper and some colored felt pens “generously” provided on each table. June vividly recalls whispering into the ears of the participant seated beside her: “*Why did we land ourselves here? She is going to ask us to draw!*” Yes, how true!! At the beginning of the workshop, they were each asked to introduce themselves through an image. It was an undeniable struggle. Everyone initially tried to have a peep at each other’s sheet. Ironically, everyone received a mutual peep in return, followed by a burst of laughter, *celebrating* the empty sheets.

The process of image construction and production took time. Marilys was experientially and professionally gentle – quietly performing “participant observation” from behind – acting “disengaged” but indeed very “engaged.” Pondering deeper, June took up an orange felt pen and drew a calendar, highlighting the sixth month. Beneath the sheet, she drew the image of some flowers in red (Image 1).

Fascinatingly, what a “story”! Never in life had June deciphered “herself” in this manner. The sixth month reflects *her name* “June,” flowers representing the month of June which in *her understanding* is associated with springtime. In terms of colors, orange, to her signifies realms of *nature*. . . The very nature of her *conceptualization of self* and her “name” at baseline! The red flowers signified her fiery anticipation for her PhD confirmation viva then approaching. Wow, how rich a data asset! In a real sense the process of art production makes the *knowledge of self* and its *levels of development* “visible.” This exercise illuminated the importance and richness of this humble methodology and how June should strive to best incorporate it into her research despite some prior disagreements that drawing would never fit the social-medical research arena.

Image 1 June’s personal encounter with the art of “self”



4 The Postmodern Turn: The Use of Drawing Among Vulnerable Populations

Phenomenological research is frequently a way in which art is used in an attempt to grasp the essence of experience in a thematic way (Van Manen 1997). However, in deciding on the methodological framework, we were propelled to also incorporate postmodernism, along with phenomenology (to capture essences of lived experiences), in hope that it would enable us to dredge deeper into subjective realms that have yet to be explored. Postmodernism argues that realities are constructed within specific social and cultural contexts (Myanmarese and Vietnamese in our research), which enable the meaning of realities to be understood within a particular context (Liamputtong 2013). Within the envelope of postmodernism, all insights are treated as legitimate without preference over the other (Grbich 2004; Liamputtong 2006). Interestingly, postmodernism permits the emergence of multiple identities on the basis that historical, social, and cultural knowledge shaped within the confines of race, class, gender, and religion (Angrosino 2007; Liamputtong 2006; Borer and Fontana 2012). This explains the similarities and dissimilarities in the expressions of drawings among mothers from both countries and even within Myanmar's subethnic groups.

Access to knowledge is understood as the ability of one to provide "warranted assertions" – warranted with regard to the truth, while assertion being language (Stein 2000; Eisner 2008). Various ethnographic studies in the scope of infant feeding among immigrants have been conducted in the past to "listen to" the narratives of migrant and refugee women who have resettled in Australia (Liamputtong and Naksook 2001; Maharaj and Bandyopadhyay 2013; Gallegos et al. 2014). However, in the mid-twentieth century, it became increasingly evident that knowledge and understanding is always not reducible to language alone (Eisner 2008). This awakening persuaded the academic environment to be more responsive to new methods of investigation (Arnheim 1966). We contend that in this scope of study, the postmodern methodological framework has the capacity to steer the research in a new direction with the advent of arts-based inquiry (Knowles et al. 2008; Liamputtong and Rumbold 2008). Furthermore, an increasing number of arts-based research has successfully used postmodernism as its backbone (Fernandes et al. 2014; Liamputtong and Fernandes 2015; Liamputtong and Suwankhong 2015; Suwankhong and Liamputtong 2016; Benza and Liamputtong 2017).

5 The Drawing Method

This study was driven by the suggestion that gathering visual data from participants of vulnerable backgrounds could enable us to access the subtle, hard-to-put-into-words aspect of knowledge that might otherwise remain obscure or overlooked (Weber 2008). Additionally, artistic productions also give rise to a new symbolic visual twist to plain old texts, shattering our commonplace perceptions and beckoning us to think outside the theoretical box. Thus, the power of art helps to project the

research findings across a wider audience in a stronger manner because “seeing is believing,” both literally and figuratively. Drawings also powerfully help ratify someone else’s gaze and viewpoint and allow us to be absorbed into their experience for a moment. In short, artistic images (drawings) creatively help us generate new insights, ways of understanding, and also promotes ethical awareness (Bergum et al. 2008). The process of drawing is not solely a rational or emotional response but simultaneously involves both the heart (through artistic expression) and mind (through theoretical and analytical considerations) to work together. This was evident in all the images obtained from this study as mothers made meaning (rationalized) their experience as they drew. The rationalization was not solely confined to responding to the drawing prompts but it initially helped mothers unleash stories of their life.

Despite being a powerful tool to capture valuable subjective experiences, drawing is best used in conjunction with other research methods such as interviews or focus group discussions (Guillemin 2004; Liamputtong et al. 2008, 2015). For a number of decades, researchers have successfully engaged children in studies involving “draw and talk” or “draw and write” techniques. In agreement that children struggle to articulate themselves through words, these techniques have contributed to rich data pertaining their perceptions, views, reflections, and phenomena (Angell et al. 2011; Liamputtong and Fernandes 2015). However, of late, scholars have successfully incorporated drawing as a research method among women and adults in the area of health and illness (see Broadbent et al. 2004; Guillemin 2004; Liamputtong and Suwankhong 2015; Suwankhong and Liamputtong 2016; Benza et al. 2017). Despite adults naturally having the greater ability to convey their narratives compared to children, the depths of data gained from adult participants through drawing of images has been surprising (Guillemin 2004; Guillemin and Westall 2008; Liamputtong and Suwankhong 2015; Suwankhong and Liamputtong 2016; Benza et al. 2017), thus, suggesting that images produced by adults could be a hallmark in gaining deeper access to the sub- and unconscious experiences that construct our worldview.

6 Drawing in the Context of Participants from Refugee Backgrounds

It is not uncommon that research involving the “stories of life” and experiences of individuals from refugee backgrounds are being expressed in sheer words (Liamputtong 2002; Niner et al. 2014). Here, we do not disagree that the aforementioned means of data collection is untrue, but instead contend that the data obtained by those forms could be limited due to their nature and that trauma, displacement, and oppression render participants unassertive. As suggested by Lenette and Boddy (2013), we too agree that prompting participants to produce artworks could seek nuanced perspectives of sensitive themes, allowing the emergence of richer sets of data rather than focusing on speech alone.

Before going further, the use of arts-based research methods, with attention to data in forms of drawings, is not new in the “refugee” research sphere. A study was conducted to conceptualize the understanding of health and illness among refugee children from Burmese ethnic backgrounds (Fernandes et al. 2014; Liamputtong et al. 2015), while Benza et al. (2017) used this method of data collection to understand the experiences of motherhood among Zimbabwean women in Melbourne. Driven by their success, we contend that the usage of this method to understand how women of refugee backgrounds construct their patterns of beliefs surrounding motherhood and infant feeding pre- and post-resettlement would lend a significant strength to the literature.

7 The Real-World Application of Drawing in Our Research

While the abovementioned researchers gained meaningful artwork from their participants, this journey of using drawing methodology among women of refugee backgrounds from Myanmar and Vietnam in our study was a struggle. Our initial months of attempting to obtain visual data from mothers was exceedingly bleak. Despite applying the techniques gathered from the workshop, having Pranee’s prominent qualitative expertise and the privilege of working alongside two experienced bicultural workers, we were repeatedly faced with rejection when it came to artwork. We knew every individual had the capacity to draw but it became increasingly evident the main problem was June’s ethnicity during immersion in the field work (She is Malaysian Indian by ethnicity). June’s different ethnic identity made mothers feel reluctant to share their visual stories with her. At the beginning, June attempted to distance herself from the mothers during the phase of art production, either by walking out of the research “area” during the art exercise or suggesting that mothers draw during the interval between the first and second interview visits. However, Pranee suggested that this method would hamper June’s ability to observe mothers through the process of art production, which is vital for analysis of drawings (Gill and Liamputtong 2014). Pranee, Wendy, both bicultural workers, and June, at several times, gathered to discuss a solution to this issue.

After about six months of fieldwork, we eventually learnt the “art” of requesting images in a culturally appropriate manner. This consolidates that increased engagement and exposure in fieldwork enhances trust between researcher, bicultural worker, and participants (Liamputtong 2006). Below we share some tips, tricks, challenges, and solutions gathered through the journey of fieldwork which could inspire researchers who share a similar interest in obtaining visual data from women of refugee backgrounds.

7.1 Participant: *“I Am Sorry, I Cannot Draw”*

The study initially focused on recruiting 30 mothers from Myanmar (Karen, Karenni and Chin ethnic groups). However, after the first nine interviews, despite follow-up interviews and consent to participate in artwork, we did not succeed in getting any visual data, and mothers were also unwilling to share their lived experiences verbally

(transcribed verbatim were closed ended answers). This led us to take a step back to review/reframe the research approach should we desire to proceed on this research path. We began with an awareness that only a handful of researchers have thus far worked alongside women of refugee backgrounds from Myanmar (Niner et al. 2013). Additionally, we were also informed that access to these participants itself has been difficult, and it would be more so with more attempts to request visual data from them. We contend that women from refugee backgrounds have battled oppression and struggle with trust and confidence because of their contact with persecution. Also, limited access to resources pre-resettlement has led to the feelings of powerlessness, insufficiency, and incapacity. This cascade of experiences has contributed to an enormous propensity to suppress feelings and stories.

The initial plan was to conduct the drawing exercise at the end of the interview. It was only then that the art materials were handed to mothers. The reason to this approach was to encourage comfort with the research process and team first, and using drawing downstream as means of validating verbal data. Since the plan was unsuccessful, a few “trial-and-error” adjustments were made, such as: (1) Adding another cultural group (Vietnamese) just in case the research fails to reach its purpose. A balanced number of Myanmar and Vietnamese mothers were recruited. Obtaining artwork from Vietnamese mothers was easier due to their artistic nature; however they too rejected drawing initially. (2) Adding another subethnic group from Myanmar (Kachin) who is known to be more outspoken and expressive. The incorporation of the Kachin ethnic group gave us the confidence to derive proper techniques when researching mothers from Myanmar. (3) Drawing materials would be visibly introduced as soon as the mother consented to artwork, in hope the participant will understand what the process entails from the start. In this manner, the invitation to draw would not shock the mother. (4) The drawing of perceptions and experiences will be encouraged from the start and mothers were encouraged to sketch when they felt like it. (5) Participants will also be prompted and encouraged to draw at the juncture when the team discerns one’s struggle to express the idea verbally. The team became sensitive to cue words such as “I don’t know how to explain,” “It is hard to describe.”

Here is an image and some verbatim quotations reflecting the pathways from which the research team formulated our conversation among ethnic Kachin mothers. The ethnic Kachin mothers were the first group of women from Myanmar who got us all inspired that gaining images from Myanmar women was not a “mission impossible” (Image 2)

Image 2

June: Can you tell me an experience to having your baby at your breast for the first time?

Participant: It’s beautiful. . . . I just don’t know how to describe it?

June: Of wow. . . . That must be incredible. . . . Would you like to draw something about the feeling? It could be anything at all. . . . There is no right or wrong. . . . Your experience is so special to my research. . . .

Participant: Hmm. . . . It’s just like this. I am smiling as soon as I saw my baby and feeling her latch on my breast. I’m carrying her and she is attaching to me. . . . This is our first time being together. . . . I used the brown color because our skin was touching and I am Kachin and my skin is brown. . . .

Image 2 Experiences of seeing and breastfeeding their babies for the first time after delivery. This is an experience that mothers struggled to narrate. Prompting an explanation of the indescribable engendered powerful images, concepts of this image are founded in their religiosity



7.2 Research Team: “That Is Okay...It Must Be Hard for You... Let’s Move On... Now This an Interesting and Brilliant Concept... Would You Like to Sketch It for Me.”

After obtaining rich, visual data from the Kachin mothers, the now blooming research technique was carried to mothers from other ethnic groups. Along the process of data collection, it was understood that empathizing with the mother’s rejection to draw was important as it established participant-researcher rapport, trust, and comfort. It was observed that the quality and richness of data increased as the research team gently affirmed and encouraged the mothers. Their past experiences of constant discouragement led to their struggle with confidence and self-esteem. Thus, *empathy* and *encouragement* was the *key* to unleashing their artistic ability. This approach finally yielded visual data from Karen and Karenni mothers. They could share their visual perception of experiences, while waiting patiently for their construction of thoughts. Imaged 4 and 5 were produced by a Karen and Karenni mother. Through observation, the sketches from Karen and Karenni mothers are simpler compared to those of the Kachin mothers whose images were more colorful. Karen and Karenni mothers choose not to use the provided felt pens and crayons but instead asked for the pen that June

Image 3 This image illustrates the bonding during breastfeeding. It was initially difficult to get the mothers from both subcultures to share their stories. However, this rich piece was attained through continued engagement



was using while jotting her fieldnotes. This portrayed deep humility and simplicity. The sketches by Karen and Karenni mothers were delicate (Image 3).

Image 3

Participant: Breastfeeding makes my baby close to me. . .

June: Thank you. Would you like to tell me more?

Participant : No

June: Would you like to draw that sense of closeness for me?

Participant: I cannot. . . But I will try. . .

Participant: (Here this mother seems unsure how to hold the pen but I kept affirming her that she is doing well as she drew this beautiful stick-human image). . . During breastfeeding I always hold my baby.

7.3 Participant: *"This really unleashes my past. . . I have never seen myself capable"*

Here, we highlight drawing as a means of empowerment especially when used with women from vulnerable backgrounds. The iterative process of emphasizing,

encouraging, and affirming gave mothers the power to convert what they deemed as an incapacity into a form of power (through their art work). During fieldwork, June observed empowerment among ethnic Chin and Vietnamese women. The Chin and Vietnamese refugees arrived in Australia without their extended family members, following a deeply traumatic resettlement journey. In countering this, the research team persistently reinforced with mothers that their stories were very important and could be a means of encouraging mothers in the near future.

Here, we argue that the process of visual image production unraveled some traumatic aspects which they had never discussed in the past. The process of artwork production, hence, had a therapeutic effect in their lives. While the struggle in artwork production among ethnic Chin mothers was nested around oppression, poverty, and discouragement, the Vietnamese relayed their struggle with artwork as a status quo issue. In contemporary Vietnam, art was only encouraged in primary school as it was seen as a task of children or the “immature.” Culturally, it is also perceived that the job as an artist is undertaken by the outcast and least privileged in society. The conversations in the charts below are aspects of communications that took place between the research team and participants during the process of engaging and building trustful relationships. The verbatim reflects questions pertaining motherhood and the meaning of infant feeding in their cultural perspectives.

Conversation A (Chin)	Conversation B (Vietnamese)
<p>Participant: “In our Chin culture. . . the <u>child is a mirror image of the mother</u>.”</p> <p>June: Would you like to draw this thought on motherhood?</p> <p>Participant: Yes I could since I already started talking on it. <u>It makes it easier</u>. . . Well, I rejected all your initial drawing prompts.. I am so sorry.. I struggle to draw. . . When I was little I loved drawing . . . but my mother told me I’m wasting paper and wasting money by drawing. . . So I stopped. . . This is the next time (after 22 years) that I am drawing again”</p> <p>“Looking back .. I still can draw. . . This really unleashes my past. . . I have never seen myself more capable”</p>	<p>Participant: I needed to undergo some radiation treatment. . . <u>it will harm the baby</u>. I felt like I <u>only had one choice</u> which was to opt for the formula milk. Just like the fish. . . <u>it only has one choice</u>, it can only be in the water to continue living. . .”</p> <p>“Now that I have drawn this picture I wonder.. I have <u>never expressed this feeling to anyone before</u>. . . Thank you for asking me to draw. . . I feel a big burden released”</p>

In short, women from refugee backgrounds struggled to produce visual data initially. However, after some interventions, we succeeded in gaining valuable insights from their life stories. First and foremost, it was fundamental, that we were sensitive to their resettlement issues as subjectively as possible – by “going into” their situation. This enabled the participant to establish a sense of security and trust with the research team. This subtheme while highlighting the multiple challenges that refugee women undergo, also demonstrates ways in which we can enhance maternal sense of agency over the stresses of daily living.

8 The Refugee Perspectives of Infant Feeding

The visual data (in the form of drawings) described the participants' lived experiences in multiple dimensions. Mothering and infant feeding in their cultural understanding begins with pregnancy where the mother is watchful of her food and bodily conducts. This extends through parturition in order to counter the perceived thermodynamic disequilibrium due to the loss of blood and energy from the childbirth process. Traditionally, the new mother is surrounded and supported by female family members who provide her with moral, verbal, and physical support in terms of house-keeping and preparation of culturally prescribed meals. However, mothers experience a "disconnect" in Australia where they are not only separated from their primary support networks but also faced with the need to navigate the Western healthcare system and new societal culture. While breastfeeding was the norm of infant feeding among Myanmar mothers, the cultural "shift" caused by resettlement led some mothers to opt for formula feeding. Knowledge on the goodness of breast milk and rooted spiritual beliefs encouraged breastfeeding in Australia. Conversely, formula feeding is the current trend of infant feeding in contemporary Vietnam. Despite being from the less privileged population groups, most Vietnamese mothers in this study portrayed some degree of mimicking the perceived modern-world trends, while those who breastfed their babies were driven by determination and sacrificial love that was rooted in their conceptualization of God.

From our observation, there was no vast difference between the type of images produced by mothers from Vietnam and Myanmar, despite mothers from Vietnam being more corporeal about their drawings expressions – focusing on bodily notions. Chin mothers struggled to engage with drawings, while the Kachin mothers drew confidently when prompted. The Karen and Karenni mothers tended to draw fine-stick sketches, gaining confidence through successive interviews.

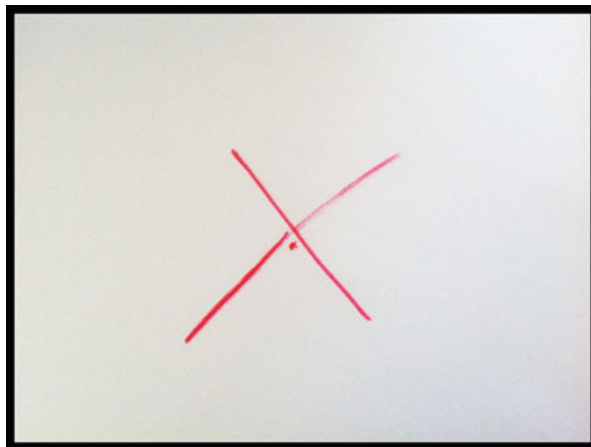
9 What Women Use Drawing For

Through the journey of data collection, a vast spectrum of artwork that dictates many stories and notions was obtained. Visual data unravels a deeper understanding of subjective experiences. Participants in this study used drawing to express several themes:

9.1 To Illustrate a Location

Mothers from the Karen culture traditionally bury the placenta of their newborn immediately after delivery. Mothers in this study did not have the opportunity to continue this cultural practice due to lack of cultural information within the Australian healthcare system. This artwork helped mothers unleash the importance of cultural beliefs for their child's well-being. While mothers were able to list the locations for burial, they were unaware of the meanings these burial sites held. The process of meaning-making that takes place during the process of art production

Image 4 Location (*dotted*) is where the placenta is buried. The color (*pink*) used in this sketch aided in meaning-making of the burial site: for the child will be loved due to the frequency of people passing by the busy junction



enabled mothers to point out the accurate site of the burial and later explain the meaning behind the cultural location (Image 4).

9.2 To Illustrate the Concepts of Motherhood

Mothers, including those in this study, conceptualized themselves as carriers of multiple identities. They juggle roles as nurturers, protectors, and role models. They too feel that by nature they contribute to the well-being of their children and battle struggles and sacrifices. The use of drawing as a research method unleashed some notions of motherhood that may have not been possible via conventional research methods.

9.2.1 Shelter

Mothers from refugee backgrounds used the image concepts of hands and trees to illustrate their worldview as nurturers. In terms of shelter to their children, mothers also used the concept of trees to illustrate this theme. In the Myanmar culture, trees hold a significance of strength. An ethnic Karen mother mentioned that only a “strong tree could shelter people from the sun.” She attributed this to the torrid summer heat in Brisbane, a season that her children associated with picnics. She adds: “Everytime we go to the park, the first thing we do is to find a tree that could give us shade.” Here, she conceptualizes that a good mother is one who could be a good shelter and refuge for her children (Image 5).

9.2.2 Mirror

An ethnic Chin mother conceptualized motherhood as a mirror (Image 6). She believes that her characteristic traits will be mirrored in her child. She adds that this cultural belief encourages her to watch her conduct vigilantly

Image 5 Motherhood as a good tree that could shelter from heat

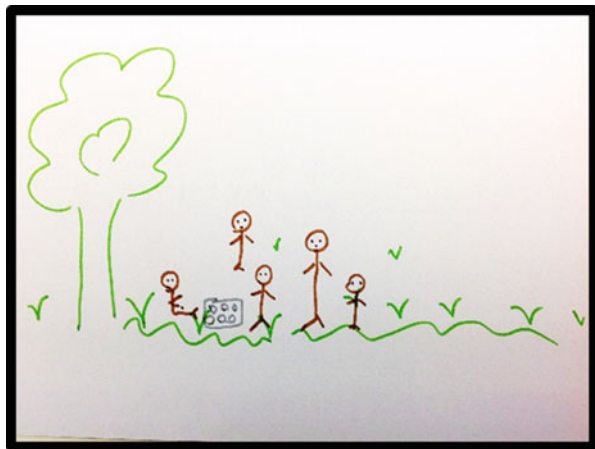


Image 6 The weakness after childbirth, like a snake that is shedding its skin



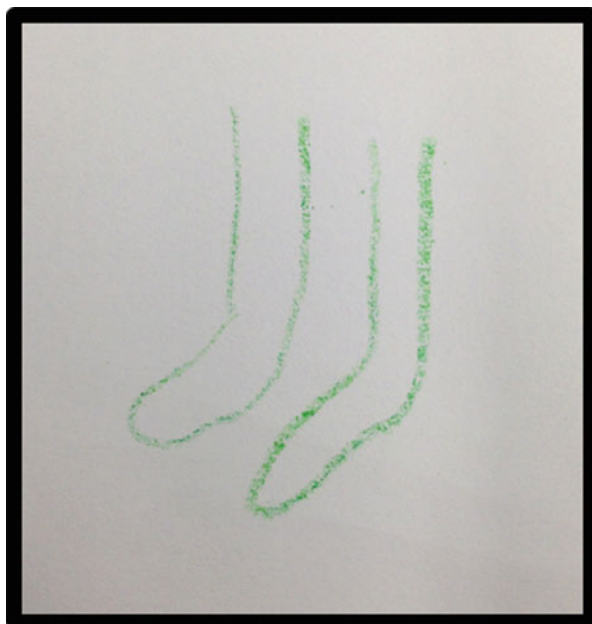
9.2.3 Shadow

Mothers also perceive breastfeeding as a hidden act. While discussing this, a Vietnamese mother explained as she drew: “Mother’s role is so important in the child’s development, however it’s. . .often undervalued.” This feeling reminded her of the traditional Vietnamese wedding family photograph where their mothers look mundane and stand at a distance.

9.3 To Illustrate Vulnerability

The initial postpartum period in traditional cultures is perceived to be a phase of vulnerability for the mother. While this vulnerability is frequently described in literature (Liamputtong 2000; Chu 2005), it was interesting to understand how women pictured

Image 7 Socks to keep the new mother's body warm after childbirth



this state. Vietnamese women in Liamputtong (2000) call it a period similar to that of “crab shedding its shell.” Likewise, a Vietnamese mother delved into her memory of seeing snakes changing their skin during her childhood years. She exclaimed: “The period after childbirth is that is like a snake changing its skin We are so weak. . . We need to hide in a safe and dark place to be protected from danger” (Image 6).

9.4 To Illustrate How Mothers Counter the State of Vulnerability

During the period of vulnerability, mothers abide by some culturally prescribed rituals that perpetuate the preservation of bodily heat to counter the state of vulnerability. While Vietnamese mother perform a ritual known as “mother-roasting” to regain their health for the motherhood tasks ahead (Rossiter 1992; Liamputtong 2000; Groleau et al. 2006), Myanmar mothers keep their bodies warm by sitting by a fire. A Karen mother drew an image of a pair of socks to illustrate how she kept her body warm in Australia. She wore thick socks instead as homes in Australia are structurally different and not suited for fire-based rituals, which is vital during the confinement period (Image 7).

9.5 To Illustrate the Freedom in Australia

Mothers from Myanmar and Vietnam underwent moments of persecution and oppression prior to arrival in Australia. Upon arrival, they expressed the freedom of being a

Image 8 Experience of freedom, peace and tranquility in Australia



big country of valleys and terrains as birds flying in the sky. They expressed that they could hardly bask in such beauty during the distressful journey of fleeing their homelands. These hardships helped mothers to build resilience and endurance which was vital for adaptation into a new dimension of motherhood in Australia. Image 8 portrays an expression of their freedom and joy of living in Australia (Image 8).

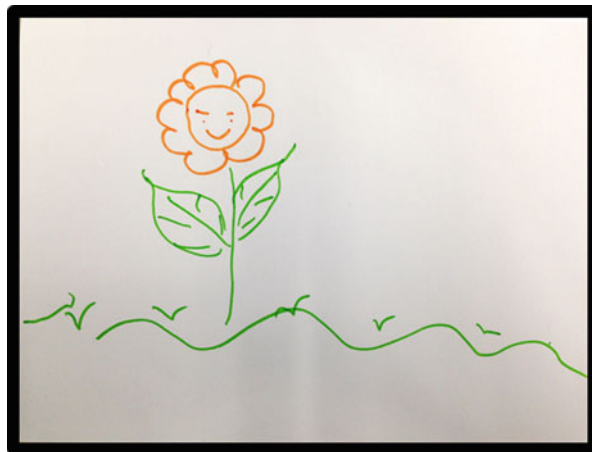
9.6 To Illustrate the Goodness of Breast Milk

Breast milk has been long known to be the best food for infants. Mothers from refugee backgrounds too agree with this. While breastfeeding is recommended for the numerous health benefits it bestows upon mother and baby, it also provides the baby with a unique species-specific nutritional and immunological treasures – the mother’s bodily goodness and antibodies. An ethnic Karen mother drew this image when illustrating her perception of “breast milk is best.” She highlighted that the nutritional and immunological properties from her body helps her baby, which she describes as a flower “blooming” in radiance, health, and glory. She believes that breast milk is the continuance of nurturing that begins at pregnancy. In her perspective, this image is a representation of her Christian perspective of “bloom where you are planted,” which expresses that a child is a gift to the family in the Christian perspective (Image 9).

10 Conclusion and Future Directions

Through the valuable images gathered, we could conclude that visual data in the form of drawings from mothers of refugee backgrounds, driven by postmodernism, will be a powerful means of driving healthcare practice and policy development to

Image 9 The radiantly blooming flower, a representation of “breast milk is best”



the next level as it unravels perspectives beyond cultural understandings. Despite this research method facing rejection as a “mission impossible” initially, its success here is a proof that women from refugee backgrounds could engage in visual arts-based research. It is hoped that the tips and tricks listed above could be a means of encouraging more researchers to invest in studies that involve women from refugee backgrounds. The messages projected from visual data are powerful as it helped participants to contemplate and delve deeper into level of consciousness that are difficult to express by words. The use of colors related to their feelings also unmasked perspectives that words could not describe. We found the postmodern research approach appropriate as it seeks multiple truths. It was interesting to see various principles emerge as participants were given the freedom to express their worldview in whichever manner suits them best.

The rise in political agendas worldwide continues to displace a many vulnerable people from third world nations daily. This has a significant impact on women in particular, as they not only battle losses, but also shoulder the need to shelter their innocent charges. While from the public health perspective, we are unable to control their displacement, we argue through these findings that drawing could be a powerful means of gaining access to their subjective and hidden experiences of trauma for intervention purposes. Additionally, drawing could also be a means of soothing disquieting feelings of their journey, as art could be a meaningful therapy for people who have never had a chance to be heard.

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Understanding Refugee Children's Perceptions of Their Well-Being in Australia Using Computer-Assisted Interviews

102

Jeanette A. Lawrence, Ida Kaplan, and Agnes E. Dodds

Contents

1	Introduction	1778
2	Theoretical Grounding	1779
2.1	Grounded in Respect for Refugee Children	1780
2.2	Grounded in Refugee Children's Expressions of Their Well-Being	1781
3	Features of CAIs	1781
3.1	CAIs Affirm Children's Agency and Control	1781
3.2	CAIs Present Accessible and Attractive Interfaces	1782
3.3	CAIs Yield Data Suitable for Quantitative and Qualitative Analyses	1782
4	Two CAIs for Researching Aspects of Refugee Children's Well-Being	1783
4.1	People and Places in Your Life	1783
4.2	Appropriateness and Relevance of the People CAI	1784
4.3	Living in Australia	1787
4.4	Appropriateness and Relevance of <i>Living</i> CAI	1787
5	Conclusion and Future Directions	1789
	References	1792

Abstract

Children from refugee backgrounds have the right and the ability to contribute to research knowledge. But they need researchers to develop methods that enact

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1777

respect and are theoretically appropriate. This chapter describes a methodological approach to understanding the well-being of children from refugee backgrounds from their own perspective. Two computer-assisted interviews (CAIs) were developed as research tools that enact respect for refugee children by facilitating young refugee participants' agency and engagement, using accessible interfaces with child-friendly, age and culture appropriate tasks, and instructions that enable children to express their views with confidence and comfort. *People and places in your life* and *Living in Australia* invite children to work on and evaluate quantitative and qualitative tasks and questions. Two illustrative studies grounded in respect show how the data constructed in these CAIs are suitable for analyses of themes and trends, standout features, and personal meanings as the basis of group comparisons and textual analysis of individual profiles. The usefulness of the methodology is discussed in relation to the need to understand the perspectives of refugee children and other children about their well-being.

Keywords

Refugee children · Respect · Theoretical appropriateness · Computer-assisted interviews · Thick description · Textual analysis · Individualized profiles

1 Introduction

Children constitute over half the 60 million people who are currently leaving their homes to seek refuge from war, violence, or persecution. Many children resettle in other countries, either with their families or guardians, or as unaccompanied minors. Their plight causes great concern among governments, practitioners, and researchers about how well these refugee children are able to adjust and thrive. International, national, and local authorities and agencies need positive and negative indicators as the evidence base for fostering the well-being of refugee children (Lippman et al. 2009; Measham et al. 2014). These bodies are not well informed, however, about children's views of what supports and inhibits children's well-being in resettlement. Consequently, Lippman et al. (2009), in reporting to UNICEF, argued that any measures designed to uncover disadvantaged children's well-being and "well-becoming" needs information from the children themselves if it is to "identify the factors that make them happy, motivated, and successful as children" (p. 626) (see also ► Chaps. 115, "Researching with Children," ► 99, "Visual Methods in Research with Migrant and Refugee Children and Young People," ► 100, "Participatory and Visual Research with Roma Youth," and ► 107, "Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds").

This chapter discusses the development of a methodological approach to understanding the well-being of children from refugee backgrounds that appropriately centers on children's perspectives. The method is the computer-assisted interview grounded in terms of ethical appropriateness and theoretical relevance.

Computer-assisted interviews (CAIs) have been used by other researchers with vulnerable children when researcher sensitivity and researchee confidence and

enjoyment are important, for example, for children with autism spectrum disorders (Barrow and Hannah 2012), for children anxious or concerned about clinical interviews (Dolezal et al. 2012; Bokström et al. 2015), and for children reporting their sexual behaviors (Connolly 2005). The accessibility of digital programs gives young research participants the kind of control and confidence not available in paper and pencil or face-to-face methods. They give the young participant autonomy in responding to attractive, reasonable, and safe means of expressing their views (e.g., de Leeuw et al. 2003; Barrow and Hannah 2012).

The chapter is organized in five sections. The theoretical grounding of computer-assisted interviews (CAIs) is followed by a description of how CAIs translate respect into action and how they enable refugee children to express their sense of well-being. A fourth section presents a pair of CAIs with illustrative studies of their usefulness. The final section discusses the suitability of using this CAI approach with refugee and other vulnerable children and the implications for cross-cultural research.

2 Theoretical Grounding

Methodological development properly begins with theoretical questions that frame the appropriateness and usefulness of the measures used. Toomela (2011) makes a critical analysis of how contemporary psychologists employ quantitative and qualitative methods in ways that violate the principle of “questions come before methods” (p. 47). In the physical sciences, Toomela argues, methods are typically used to address theoretically generated questions – by being selected from available methods on their suitability for those questions or being specifically created to address new questions. In psychology (and other social sciences), it is not unusual for the choice of methods to precede the formulation of research questions, and for measures then to dictate analyses, and in the process, to severely limit contributions to knowledge. A prime example can be found in evaluations of social programs. When method selection dominates, questions about the value of a program may be sacrificed when peripheral details are reported instead of the effects of program delivery. Researchers may fall back on reporting, for example, the number of people who attended a program and how often, because the methodology cannot address more theoretically telling issues, such as the immediate or lasting effects of the intervention (Patton 2011). Cairns and Dawes (1996) make a similar observation about the tendency to count instances rather than effects of violence: “We can count exposure to violence items but this does not help us gauge their differential impact” (p. 136).

The tendency to method-driven research can be particularly dangerous in cross-cultural and culturally oriented research. Method-by-group-mismatches occur when methods are “parachuted” from one culture (usually Western) to another, despite the inappropriateness of asking some cultural groups to respond to essentially Western tasks and questions with little meaning for them (Goodnow 2014). Callaghan et al. (2011), for instance, criticize “researchers who parachute their procedures from Western labs into cultures where even asking a question one

knows the answer to is considered odd” (p. 112). Some methods for asking seemingly universal questions do not transpose well from one culture to another. Community workers, for example, report that asking young people from Middle Eastern Cultures about their self-esteem is to ask them about something that has no reference point and no linguistic meaning for them. Ignoring cultural differences has promulgated deficit models of indigenous cultural groups, despite successful integrations of their traditional approaches to healing with biomedical care (Hirsch 2011). In cross-cultural research, methods need to be appropriately grounded in respect and the application of theory to particular groups. Accordingly, the CAI methodology is grounded in two concerns: the ethical concern to demonstrate respect for refugee children whose perspectives are under-represented in cross-cultural research and the theoretical concern to enable these children to express their views on their well-being.

2.1 Grounded in Respect for Refugee Children

Respect is an ethical principle that defines people’s rights, including the rights of young research participants in the UN Convention on the Rights of the Child (United Nations 1989; Beazley et al. 2009). It is a guiding rule for applying rights directly to specific human interactions. Rights do not become practical realities automatically because they are rights. Rights must be enacted, and in research, enactment comes from the decisions and choices that researchers make specifically under the direction of the respect principle. Researchers have a particular obligation, for instance, to *enable* the self-expression that is the right of refugee children (United Nations 1989; Lawrence et al. 2015).

Coupled with a strong focus on person-oriented data, respect directs CAI research to treat every research participant as an individual with unique as well as common experiences to contribute to knowledge (von Eye 2010; Bergman and Wangby 2014). This avoids reducing individuals’ contributions to quantitative analyses of group trends where the individuals’ responses are treated as replaceable slot-fillers (von Eye and Bogat 2006). It also avoids handling qualitative data as entries in banks of quotes from which researchers may selectively “cherry-pick” material supporting their own positions (Morse 2010; Toomela 2011; Mazzei and Jackson 2012).

The patterns and themes in people’s data may only be revealed with careful analysis (Steinberg 1995) that is dependent on appropriate representation of what people said or did in context so that analyses yield thick, contextualized descriptions (Ponterotto 2006). Participants’ meanings emerge in the themes they reiterate, links they make between questions and sections of data, and standout comments by which they express both typical and atypical ideas as individuals or as members of a certain group (von Eye 2010).

The CAI method is well suited to investigating children’s views of well-being, especially in light of Ben-Arieh’s (2005) complaint that children are not usually consulted about their evaluative responses to their lives.

2.2 Grounded in Refugee Children's Expressions of Their Well-Being

In general, well-being is used as an umbrella concept that reflects children's thoughts and feelings about different aspects of their lives and covers the numerous everyday experiences that add to their more and less good impressions of how life is for them (Ben-Arieh et al. 2014). Various defined and measured, the well-being concept has elastic boundaries and referents of present and future contentment, and it is always contextualized and associated with routines and expectations (Weisner 2014). Children's senses of well-being and belonging can be affected positively or negatively by their contextual habitats and circumstances as well as by events and losses, intrusive thoughts and personal characteristics (Ben-Arieh et al. 2014).

Two custom-built CAIs, *People and places in your life* and *Living in Australia*, were developed to enact respect for refugee children and their views about a range of positive and negative aspects of their well-being in Australia. Procedures were designed to give due recognition to their vulnerability to adult power (Lawrence et al. 2015). Tasks and questions were based on indicators of their well-being that emerged in practice at Victorian Foundation for the Survivors of Torture (Kaplan 2013), in consultations with professionals from multiple disciplines working with refugee communities through the Victorian Foundation (VFST) and from interviews of VFST clients and counselors (McFarlane et al. 2011).

3 Features of CAIs

3.1 CAIs Affirm Children's Agency and Control

Organizing research environments to affirm children's agency and control is a direct application of respect for vulnerable refugee children and a practical recognition of their rights. At recruitment, each child is asked explicitly for his or her informed consent to participate, irrespective of prior parental consent. The accessibility of digital programs gives young research participants the kind of control and confidence not available in paper and pencil questionnaires or face-to-face interviews (e.g., de Leeuw et al. 2003; Barrow and Hannah 2012). Young participants are invited to interact with the computer program as the primary focus of the interview session. The researcher is presented as someone who sits beside the child to assist, but does not take charge. Most children prefer to work on the keyboard themselves and to be helped with words and spelling. This change in the usual center of control goes some way towards dispelling the reluctance to disclose information that other researchers have found with young refugee samples, particularly among unaccompanied minors (Kohli 2006; Chase 2013; Goodnow 2014). Confidence is critical, but only when it is genuinely related to agency.

In the data construction phase, the CAIs provide the children with a facility to personalize their expressions; create and manipulate personally generated diagrams of the people who help them and review and if they wish, revise responses

(e.g., changing entries between “helps me feel better in myself” to “doesn’t help me feel better in myself” lists). An invitation to evaluate their research experiences is an integral part of agency grounded in respect. This innovation is easily presented in the digital environment.

Digitization makes it possible for the exchange to follow a participant’s line of reasoning using branching sequences and asking for explanations, with prompts. Pathways and specifics emerge out of a participant’s patterns of response in real time. For example, in *Living in Australia*, participants rate their level of worrying by choosing a color-coded and labeled button on an ascending scale. The next screen then returns their chosen button and asks for an explanation as a sentence completion: “I worry a little bit/more than a little bit because. . . .”

Standard off-the-shelf measures do not readily encourage the emergence of novel insights that young participants can generate when typing in a sequence of exchanges. One 8-year-old Iraqi girl, for example, made a surprising choice of computers as what helped her the most. She explained this uncharacteristic choice. Her brother whom she adored was still in Iraq. “Because I have facebook. I can write to my brother, say nice things to him, chat.”

3.2 CAIs Present Accessible and Attractive Interfaces

All story agents are illustrated as universal human images, colored blue to avoid racial discrimination or stereotyping. Instructions are brief and presented in uncluttered working spaces supported by pop-up menus and simple navigation buttons and arrows. Font size is large and clear. The language is simple English, following the advice of cross-cultural counselors. For a new intake of refugees from Syria and Iraq, however, a new CAI, *My life in Australia* offers the choice of a simple Arabic or simple English version. Practice tasks and animated demonstrations introduce children to making rating and choice responses. Scenarios are illustrated and animated, with colored headings specifying whether a current question is about the story agent’s family or the participant’s. The scenarios develop in ways that are meant to convey to children that thoughts and feelings about refugee experiences are recognized as legitimate, giving serious attention, for example, to the story agent’s worries about family members.

3.3 CAIs Yield Data Suitable for Quantitative and Qualitative Analyses

Tasks and questions yield a mix of quantitative and qualitative, standard and innovative activities giving children multiple ways of expressing their thoughts and feelings about specific aspects of their well-being. All data can be downloaded as complete sequences of tasks and participants’ responses and revisions, for contextualized representation as individualized profiles. Examples of individualized profiles are shown in Lawrence et al. (2013).

4 Two CAIs for Researching Aspects of Refugee Children's Well-Being

Two CAIs ask children to comment on different aspects of their well-being in Australia in a research environment constructed with appropriate attention to respect and to children's expressed understanding of particular aspects of their well-being.

4.1 People and Places in Your Life

The *People* CAI uses accessible and well-explained choices, sorts, ratings, and open-ended comments to ask young participants to express their thoughts and feelings about: (i) significant places in their lives, (ii) being nurtured, (iii) what helps them feel better, and (iv) the research experience.

- (i) Children express their positive feelings about places by sorting named tags for home, school, and suburb into pairs of labeled baskets to describe their feelings about each place. The baskets are presented as nine randomly ordered pairs, each labeled with a positive feeling or its negation (e.g., loved or not loved, scared or not scared) building up a description of their positive feelings. They then sort the same places into "important" or "not important" baskets. Positive feelings scores for each place are constructed by reversing four negative items and range from 0 to 9. There was reasonable consistency for a sample of 49 children from refugee backgrounds, with alpha levels around 0.70 (Dodds et al. 2016).
At the end of this sorting activity, children are reshown their "important" and "not important" choices for the three places and how they can change their choices if they wish. They then are asked to type in what makes a place important for them. They are reshown the feelings they specified for home, and how they can click on any feeling to change it to its opposite (e.g., changing "lonely" to "not lonely"). These revised choices are used in analyzes.
- (ii) Experiences of being nurtured at home are expressed as children respond to the stem question, "At home how much do you think you are..." for each of nine randomly presented experiences with thumbnail illustrations: "guided, loved, looked after, listened to, protected, misunderstood, treated unfairly, hurt, upset." Children are first introduced to rating these experiences with an animated demonstration of four glasses being filled to different levels with associated progressive labels (0, "not at all," 1, "a little bit," 2, "more than a little bit," 3, "a lot"). Ratings, with four reversals, form a "being nurtured" scale, with typically good internal consistency for nine ratings ($\alpha = 0.80$ for 49 children) (Dodds et al. 2016).
- (iii) Discriminations are made among things that do and do not help by clicking on icons for each of 13 "helps" to send them to one of two illustrated lists: "helps me feel better in myself" or "doesn't help me feel better in myself." The

13 helps include social interactions (e.g., spending time with family/friends), personal achievements (e.g., people saying you did well, being proud, feeling understood), and activities (e.g., playing sport, listening to music, time alone). Children are given opportunity to change on reflection their entries to the illustrated lists and then to choose which of the 13 things help most and explain why with an open-ended comment.

- (iv) Children evaluate the CAI experience by rating it with 0–5 stars on its easiness, fun, understandability, and suitability for their age and whether or not they would recommend to a friend and why.

4.2 Appropriateness and Relevance of the People CAI

The CAI is useful as a research tool to the extent that it appropriately enacts respect for refugee children by enabling them to express themselves with confidence and ease, and to the extent that it provides evidence of their personal perspectives on their well-being.

Evaluations of *People* made by 49 children from refugee backgrounds illustrate their comfort with saying what they thought about it with their personal reasons (Dodds et al. 2016). These positive ratings were consistent with those made by 90 refugee, immigrant, and local children (Lawrence et al. 2013).

The 49 children generally gave *People* mean ratings above 4 (4.31–4.63, with standard deviations lower than 0.8), assigning it 0–5 stars on each of four bases: ease of using it, fun, understandability, and suitability for people their age. The mean rating on a “happy with the program” scale was 3.65 (*SD*, 0.56) on 0–4 scale. Comments about whether they would recommend to a friend or not revealed the children’s engagement and their concerns. Table 1 shows the patterns of recommendations with coded categories of comments and examples typed-in by 32 children (65%) who said “Yes, I would tell a friend to do this program”; 13 (27%) who were “Not sure”; and the 3 only (6%) who said “No, I would not tell a friend to do this program.”

The comments reveal children’s spontaneity and insight into their own concerns and those of their friends, and a level of sophistication in relating to the *People* activities, not only as “fun,” but for some, as something related to their own psychology, for example, “it takes away the bad stuff,” “it’s like someone was interviewing you.” Several commented that participating friends would “get more smart” or “more ideas for life” and that researchers could “get more to participate.” Undecided and declining children also displayed some sophisticated reasons: “it’s hard to explain,” “they will be angry.” In summary, these children seriously took up the opportunity to exercise their agency and to judge their CAI experience, in the process providing evidence of their abilities as well as the facility the CAI offered them for self-expression.

Evidence of different aspects of refugee children’s well-being emerged in the multiple forms of self-expression and levels of engagement that *People* invited from children. Analyzes within the person-oriented approach (von Eye and Bogat 2006;

Table 1 Patterns of Forty-nine Children's Evaluations of 'People' CAI with Illustrative Type-in Responses to Question: "Would you tell your friend to do this program or not?"

Response (Coded)	No.	Example – because ... (age in years group gender)
Yes (Helpful)	11	It could help your friend with what he's feeling (11yo O-C B) They now what they can do when they are worried (11yo I-C B) I'd tell them how awesome it is like someone was interviewing you getting to know someone (11yo O-C G)
Yes (Fun)	7	It's fun answering the question (10yo I-C G)
Yes (Fun and Helpful)	1	It is fun and it takes away bad stuff that I am worried about. I always get sad when I talk about people and my life, but this made me think how they help me and give me strategies (12yo I-C B)
Yes (Easy)	4	It is an easy program, and it will keep all your personal details safe (11yo O-C G)
Yes (Helps researchers)	4	You get more people to participate (11 yo O-C B) It will help the researchers understand what children do (11yo O-C B) It may be helpful to them like if they have any problems you might know about it (10yo O-C G)
Yes (Informs)	3	To get more ideas for life (10yo I-C B) So that they can get more smart (9yo I-C B)
Yes (Idiosyncratic)	2	It's not something that helps you get rid of bad thoughts (12yo O-C G) Some of them go to schools that teach them maths so if they look at this program, they won't need to go there anymore (9yo I-C G)
Not sure	13	It's hard to explain the program (9yo I-C G) It could feel bad for the person having a bad time (10yo I-C B) Some of it I didn't understand and I might not be able to explain what it is about (11yo O-C B) I'm not sure he likes it (11yo I-C B)
No	3	They wouldn't want to do it (10yo I-C B) They will be angry (9yo I-C B) It's a secret (9yo I-C G)
No answer	1	I do know. All my friends have done it already (9yo I-C B)

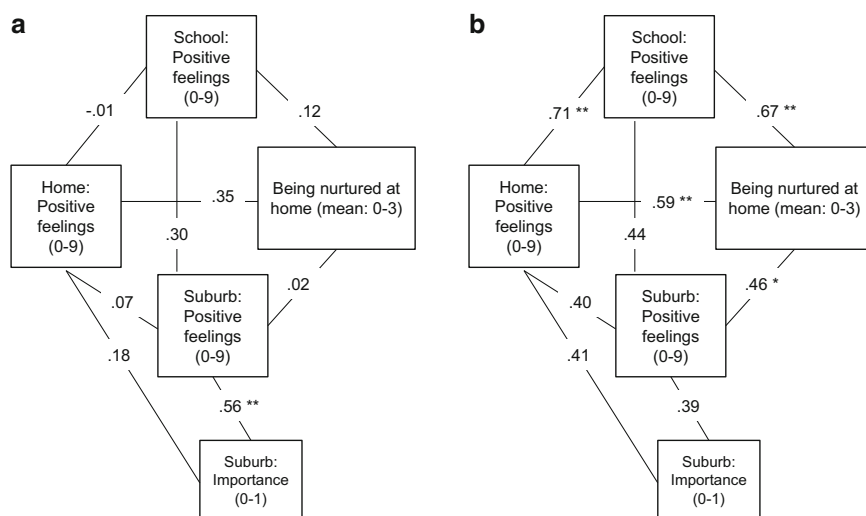
von Eye 2010) revealed, for example, a range of perspectives in what 90 children indicated helped them to feel better (Lawrence et al. 2013). Six clusters specified distinctive patterns of "helps me"/"doesn't help me" lists, and these clusters could not be identified as having refugee, migrant, or local Australian-European backgrounds, nor in relation to their age or gender, but only in their personally generated and checked lists. Clusters differed not in the possible helps that most children endorsed (such as spending time with family/friends, doing your best, someone saying nice things about you), but more finely, in the possible helps that they differentially rejected as not helpful.

While one happy cluster said all 13 things helped them, another cluster rejected sport and another rejected both having time alone and listening to music. Compared with the "everything helps" cluster, the "not sport" cluster also expressed less positive feelings about home and school and about being nurtured at home; and the "not being alone or listening to music" cluster less positive feelings about home

but not about school. This level of discrimination goes beyond simple group differences by supporting children to make considered, reflective choices and then by taking their choices seriously in identifying discriminating subgroups.

The Dodds et al.'s (2016) study also illustrates the different patterns of data across multiple forms and tasks from two groups of children from similar refugee backgrounds. These groups were living in different types of state houses in different Melbourne suburbs: 29 in high rise inner-city state housing flats and 20 in outer-suburb individual houses. Correlations between different aspects of the groups' well-being are shown in Fig. 1a, b.

Figure 1a shows how for the inner-city flat dwellers, their quite high-level positive feelings about home were not correlated with positive feelings about school or suburb or about being nurtured at home. For outer-city house dwellers, however, the comparable correlations were strong (Fig. 1b). These children were not simply expressing socially desirable feelings. They were making discerning choices when sorting their feelings about places and discriminating ratings, and these choices were not always similar. For example, one 10-year-old outer-city girl recorded no positive feelings about school. Rather than treating her extreme responses as outlier data, inspection of the patterns across all her responses suggested the probable meaning behind her unusual expression of discomfort. In typing in her reason for recommending the CAI to a friend, she said; "Because it helps people who get bullied to tell people what they feel." In her response to a final optional question about how the CAI could be improved, she was explicit, "These programs could ask how you get bullied and how you feel when you do."



Key: * $p \leq .05$, ** $p \leq .01$.

Fig. 1 Correlations for Three Places and Experience of Being Nurtured, for: (a) Twenty-nine Inner City Children, and (b) Twenty Outer City Children

Patterns of similarities and differences – of both central and outlying tendencies in the quantitative and qualitative data – pointed to the children's considered expressions of their thoughts and feelings. The quantitative/qualitative mix of data is useful for uncovering different aspects of the children's views about well-being, while fulfilling the criterion of respect for their individual as well as common contributions to knowledge. Children as young as 8 years were able to express thoughts showing their engagement with the tasks and their freedom to express their individuality.

4.3 Living in Australia

In the *Living CAI*, participants are introduced to Aya (girl) or Ali (boy), as “about your age.” In young child and teenage versions, the CAI uses illustrations and animations to present Aya/Ali's story in a series of situations with prompts asking participants to comment on Aya/Ali's experiences and any related experiences of their own (the teenage form has more requests for explanations). Young participants are told that Aya/Ali came to Australia after some bad things happened back in the home country. One situation describes how Aya/Ali is worried about family left in other countries, and another that she/he is worried about people at home at present who are sad, then angry. The CAI asks participants whether or not they have experienced situations similar to those experienced by Aya/Ali and what they were like. It then tells participants that Aya/Ali finds it difficult to engage in each of five adolescent activities because of worries (hanging about with friends, making friends, sleeping at night, getting out of bed, talking with adults). Participants then are asked to construct personal casts of the people in their lives by clicking on figures (adult, adolescent, and child males and females) and giving each person a role (e.g., father, friend). Later participants use this cast to build another diagram of who among those people help them. Then they are asked to identify what they would like to achieve or change in their lives in the next year and who could help them achieve that and how. Participants use four simple forms of response: forced choice (no, not sure, yes), Likert scale ratings with numbers and words for clarity (0, none, 1, a little bit, 2, more than a little bit, 3, a lot), constructed diagrams, and open-ended comments. The CAI records all quantitative and qualitative responses for downloading as each participant's profile.

4.4 Appropriateness and Relevance of *Living CAI*

Understandably given their vulnerability, refugee and asylum seeker children who travel without their parents are often reluctant to talk about themselves or their families to people they may see as official in any way (Kohli 2006). The specific enactment of respect for unaccompanied minors involved constructing a research environment and a set of exchanges that gave them a secure way of communicating their individualized views, or to decline to answer questions in comfort.

Theoretically, the *Living* CAI focused on worries and hopes that are prominent features of life for refugee young people (McFarlane et al. 2011). Worries have the potential to disrupt a person's well-being and to impact on their hopes for the future. Young people who are isolated from their families are mostly hoping for some form of family reunion, either under the provisions of invitational humanitarian programs or for asylum seekers, by gaining economic stability so they can independently provide for family members. Their hopes as well as their worries then are personal. Respect for these young people extends to how their views are represented in analyses (Mazzei and Jackson 2012). Lawrence et al. (2016), accordingly, recently used a close, exegetical textual analysis of the complete CAI interviews of four teenagers who arrived in Australia as unaccompanied minors.

The contextualized analysis pays due respect to the young people's constructed knowledge by noting their personalized expressions and language and by tracing their themes across their complete data transcript that is downloaded from the CAI immediately and intact. A special feature of the analysis is reproduction in table form of each participant's complete exchange with the relevant tasks, questions, and probes. The tables present the primary data that are the bases of researcher inferences. Textual analysis of the tabulated data is similar to keyed exegetical analyses used in Lawrence and Valsiner (2003) to trace the sequenced processing of a young shoplifter's crime by two police officers and by Welsh (2009–2010) to represent the multiple indicators of beginning teachers' classroom performances. This approach to data management of qualitative produces descriptions of research participants' expressions with their contextualized meanings that in Ponterotto's (2006) terms make them thick rather than thin, and anchored and contextualized rather than decontextualized, liberally interpreted descriptions of people's ideas.

The table-anchored textual analysis gives young participants the appropriate respect of working with their considered and developed thinking as the themes they repeat across time and tasks and as the specific concerns they identify. For example, all four unaccompanied minors typed comments about their worries about their families, but referred to their isolation in personal ways. One young woman made continual references to her preoccupation with family reunion, turning questions away from her foster family in Australia and onto her preoccupation with her own family overseas, commenting; "I worry a lot because I live with other family while my family is alive." A young man who had been an asylum seeker had no prospect of family reunion under the humanitarian program. He instead concentrated on his studies and his own loneliness, but commented on his need to, "concentrate on my studies and stop worrying about my family."

The fully tabulated data gave particular meaning to the young woman's ambivalence about her well-being as "a bit OK and a bit not OK," and her despair that anyone could help her. The data also made sense of the lonely young man's feeling that things were "mostly not OK," and his lack of response on who does and could help him. The tables also make the researchers' inferences and interpretations open to the inspection and scrutiny that, according to Feyerabend (1975), is a criterion for empirical research. While the full tables shown in Lawrence et al. (2016) may be confined to small numbers, they are amenable to identifying cluster subgroups and

reproduction of group patterns, consistent with the person-oriented approach (e.g., Martinez-Torteya et al. 2009).

5 Conclusion and Future Directions

The CAI methodology was developed to promote better understanding of refugee children's well-being. Two CAIs were designed to enable these children to report their thoughts and feelings about multiple aspects of their well-being and to provide representations of their meanings and emphases that allow researchers to identify the themes and stand-out features in children's expressed perspectives.

Refugee children have the right and the ability to be active and respected contributors to research knowledge. They have been through situations far beyond the normal range of family and other experiences of their mainstream peers. Many are dealing with isolation from family members along with their own dislocation, and others are trying to settle in situations that are less than optimal for children's development. Their strengths and resilience can be easily overlooked in the face of the magnitude of their traumas and vulnerability (Kaplan 2013). Whether they are reporting positive or negative aspects of their well-being, these children have significant contributions to make to a better understanding of well-being.

The input of refugee children is valuable for those seeking to promote their positive development in resettlement, and in general, valuable for cross-cultural research involving children. If service delivery and program development are to alleviate disadvantage and support development, the voices of refugee children need to be heard, as Lippman et al. (2009) reported to UNICEF. Nevertheless, the involvement of these and other disadvantaged children in research is not simply a matter of open invitations or easy applications of standard measures. Criteria apply, particularly the criteria of grounding methods in respect for the children and in the theoretical relevance of the perspectives they are asked to express.

Well-being has many facets (Ben-Arieh et al. 2014), and its meanings and manifestations in an individual child's life cannot be most productively captured with a single, umbrella concept. Nor can well-being be assumed to have the same indicators in the lives of refugee children whose background and settlement circumstances appear to be similar. The two CAIs provide evidence of some consistent concerns for younger and older refugee children and evidence of some diverse concerns that cannot be explained by age, gender, or other demographic characteristics.

Although the importance of family, for instance, cannot be overestimated for dislocated and separated children (McFarlane et al. 2011; Measham et al. 2014), family-related worries take on different proportions in how children interpret events and relationships, as the illustrative examples clearly demonstrate. Even family reunion can be framed differently in relation to unaccompanied minors' circumstances and immigration status. Places carry special significances in terms of relationships and personal identity (Christensen 2003), but again, the CAIs revealed that significant places are not uniformly interpreted. Along with the suburban neighborhood, children's homes and schools elicit different configurations of expressed

feelings, when measures are sensitive enough to capture children's personal interpretations of events and relationships. In summary, refugee children cannot be grouped together as a single, disadvantaged class that is expected to express uniform views of similar experiences.

Standard analyses of group means using general purpose, off-the-shelf measures are not likely to reveal the different views of individual group members (von Eye and Bogat 2006), or how individuals infuse the same or similar events with distinctive meanings (Lawrence and Valsiner 2003). Personal themes and preoccupations call for full, contextualized, and thick representations and multilayered analyses (Ponterotto 2006; Mazzei and Jackson 2012; Morse 2010). Unusual and novel perspectives may only come to the surface when a young person's full complement of choices, ratings, and explanations can be inspected as a whole set. Preoccupations and worrying concerns may only be highlighted when young participants are offered a variety of tasks and opportunities to reflect upon with options to revise their initial choices. The CAI method specializes in translating respect into digitized constructions and representations that give children such options.

Digitization in itself, however, is not sufficient to achieve appropriate levels of reflection and authenticity. There is a contemporary trend for data-greedy researchers to use online and computer-presented barrages of standard questionnaires. Admittedly, these are economical of researcher costs and effort, but they may offer attractive environments and participant incentives without showing due respect. Computerized or online delivery does not guarantee the appropriate address of theoretical questions. Parachuted measures can be delivered online without theoretical grounding. Theoretically generated questions also must be viewed with suspicion whenever they are presented with rough regard for cultural sensitivity or for the personal worth of a vulnerable sample (Spyrou 2011).

Attending to respect and theoretical relevance involves tailoring materials and procedures to children's interests and cultural backgrounds. Participant agency and engagement, interface accessibility, suitable tasks, and instructions all address the construction of respect-driven and theoretically relevant research using CAIs. The quality and relevance of the quantitative and qualitative data constructed using the present CAIs encourages further use in refugee studies and other areas in need of children's contributions to knowledge.

What future directions could be added to this program of methodological development? Presenting the interface in the children's own language is one possibility. This courtesy, however, requires more than translation and back-translation. It demands deep attention to the cultural nuances imbedded in language. For example, in English a "grown-up" is an adult, but in Arabic it may also be any relative older than oneself, so another child. Superficial translation may lead to participant misinterpretation of the question or researcher misinterpretation of responses. Choice of language also requires understanding that the educational language of some groups may not be the language of their heritage culture, instead, it may be the language of oppression, as for example, for Assyrian-Chaldean and Coptic groups from Syria and Iraq who had to do all their schooling in Arabic. Similarly, the relationship of minority and newly settled groups to mainstream language is by no means easily

discerned (Goodnow and Lawrence 2015). Readily acquired Street English does not serve children well for school learning.

Another direction, officially mandated in the UK, required that children be involved in research decisions and policy-making. That seemingly empowering policy, however, has not been uniformly successful in giving children confidence that they or their input are respected (Tisdall 2008).

Naturally, well-being does not exhaust the area of refugee studies. Other aspects of personal development could be investigated together with aspects of cognitive and neurological development. While the general idea of using CAIs may be suitable, partly because of the groundwork already achieved, it would be disrespectful in the extreme to succumb to using quick adaptations. Toomela's (2011) point outweighs convenience – theoretical questions must be addressed in advance of methodological attractions.

This point pertains also to adaptations of CAI methodology to the wider area of cross-cultural studies. CAIs are suitable for bringing to the fore different aspects of children's contributions to knowledge. The tasks presented to young contributors in the present CAIs were grounded in issues of theoretical and practical relevance for refugee populations. The different aspects of well-being that are particularly challenging for refugee children in an Australian urban setting may be similar to those that challenge children in other settings, but these CAIs were developed for their specific settings and concerns, and not with an eye to universalization. While worries about family dangers and family reunion are widespread across refugee and migrant groups (Goodnow 2014), the applicability of the indicators of well-being for these refugee children needs testing for their relevance to other groups. Just as no one method is a one-to-one match to theoretical concepts, neither is it automatically applicable to the concerns and needs of all disempowered and dislocated groups. Other children with well-being issues are likely to belong to indigenous and marginalized groups whose prospects are likely to be compromised by either poverty, disempowerment, or prejudice. It is advisable to consider specific aspects related to their well-being, for example, issues related to land and identity for indigenous populations. Any methodological applications also would depend on appropriate translations of respect for a specific group. In the case of asylum seekers in detention, for instance, it may not be ethically appropriate to ask for their research participation at all, when it is not possible to offer what they may see as appropriate advocates and champions with the immigration system.

Respect applies some further restrictions on cross-cultural comparisons. Theoretical questions and empirical measures are not equally suitable for all cultural groups. Their unevenness is especially pertinent when one group in a comparative study is a minority or disadvantaged group seen through a deficit lens, when compared with a mainstream group. As Callaghan et al. (2011) pointed out, measures may be a good fit for a Western group but a bad fit for a non-Western group.

In conclusion, it is not only the right of refugee and other children to communicate their perspectives on their well-being (UNHCR 1983), it is the responsibility of governments and agencies to understand their communications about what helps or hinders their health and well-being. Researchers bring rights and responsibilities

closer together to the extent that they appropriately enable children's expressions of their thoughts and feelings, represent and analyze those expressions with attention to themes and trends, standout features, personal meanings, and above all, are guided by respect for refugee children.

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Conducting Focus Groups in Terms of an Appreciation of Indigenous Ways of Knowing

103

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Contents

1	Introduction	1796
2	Defining Some Contours of Indigenous Epistemologies	1797
3	Some Literature on Focus Group Research and Lacunae Identified	1800
4	An Illustrative Example: A Focus Group Session with Teachers in KwaZulu-Natal	1802
5	Conclusion and Future Directions	1806
	References	1807

Abstract

This chapter offers deliberations around the facilitation of focus groups in a manner that takes into account Indigenous ways of knowing. Indigenous knowing (within various Indigenous cultural heritages) can be defined as linked to processes of people collectively constructing their understandings by experiencing their social being in relation to others. This chapter explores how the conduct of focus groups can be geared toward taking into account as well as strengthening knowing as a relational activity defined in this way. I suggest that once facilitators of focus groups appreciate this epistemology, they can set up a climate in which people feel part of a research process of relational discussion around issues raised. This requires an effort on the part of facilitators to make explicit the type of orientation to research that is being encouraged via the focus group session to participants. In this chapter, I offer an illustrative example of an attempt to practice such an approach to facilitation in a rural setting in South Africa.

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Keywords

Indigenous ways of knowing · Collective exploration as relational · Facilitator orientation · Focus group research · Participant feedback

1 Introduction

In this chapter, I consider the conduct of focus groups underpinned by an outlook that takes account of Indigenous ways of knowing. The chapter is set in the context of Horsthemke's (2008) statement that "Indigenous knowledges, as a discursive framework in the academy, are relatively new and have only gained currency in the last twenty years" (as cited in Wane 2013, p. 100).

When considering Western-oriented epistemologies since the beginning of the so-called Enlightenment in the seventeenth century, Ladson-Billings (2003, p. 398) states her concerns that these (still) dominate the way in which knowing is conceptualized in research literature, to the detriment of "ethnic epistemologies." She sees René Descartes' rationalist approach to knowing which he propounded in his *Discours de la méthode* (1637) as offering an epitome of how knowledge-making is defined as resting on individual thought patterns, where "the individual mind is the source of knowledge" (p. 398). She contrasts this with

the African saying "Ubuntu," translated "I am because we are," [which] asserts that the individual's existence (and knowledge) is contingent upon relationships with others. (Ladson-Billings 2003, p. 398)

Ladson-Billings suggests that these divergent epistemological perspectives are not merely matters of "preferences." She argues that the "preference" for the former kind of epistemology serves to reproduce a "dominant worldview and [attendant] knowledge production and acquisition processes" (p. 399). In the light hereof, it is crucial to revitalize alternative traditions of knowledge-construction and ways of appreciating collective processes of knowing, as offered within ethnic/Indigenous worldviews.

Like the word *ethnic*, the term *Indigenous* can be used here to denote "Indigenous peoples and culture" in different contexts (Kovach 2009, p. 20; see also ► Chap. 15, "Indigenist and Decolonizing Research Methodology"). Notably, however, authors such as Ladson-Billings and Kovach do not consider "culture" as harboring monolithic or static meanings but rather as harboring symbolic expressions which can form a basis for continuing conversation around the symbols, and a revitalization of their meanings in use (see also ► Chaps. 88, "Culturally Safe Research with Vulnerable Populations (Māori)," and ► 108, "Ethical Issues in Cultural Research on Human Development").

The point is that, as Rajagopalan (2016, p. 235) contends, it needs to be appreciated that the languages/cultural heritages of many Indigenous people "facilitate meta-rational understandings of their (human) conditions" and a "participative approach" to the cosmos (including our connectedness to all human and non-human life) but "Western science has made them . . . into the enemies of rational analysis" and in this process denigrated them. Chilisa (2012) argues that in such a

context, a postcolonial (Indigenous) research paradigm offers an orientation aimed at strengthening Indigenous worldviews (which are premised on an experience of connectedness), epistemologies (premised on the idea of knowing as a communal endeavor), and axiologies (premised on relational accountability) (see also ► [Chap. 87, “Kaupapa Māori Health Research”](#)).

With reference to research undertaken in post-apartheid South Africa, Ndimande (2012, p. 215) suggests that this would imply, *inter alia*, being attentive, especially when organizing research work that involves Indigenous participants, not to enforce still dominant understandings of what it means to conduct research – and to be attuned to the spirit of “decolonizing research.” He argues that decolonizing research presents a challenge to traditional ways of conducting qualitative research, as well as to ways of doing quantitative research. He summarizes the movement toward decolonizing research as follows:

Decolonizing methodologies can help researchers interrogate the very notion of “knowing” as well as what it is that we know and who benefits from that knowledge (Rogers and Swadener 1999). This study [referred to in his article, where Ndimande conducted focus groups with Indigenous parents of school children] involved marginalized communities whose cultural epistemologies rarely find due recognition or even acknowledgment in academe and/or in educational research institutions. Interrogating the constitution of knowledge and its function is what can translate to decolonizing research. (Ndimande 2012, p. 223)

Speaking about the premises of decolonizing research across the globe, and more specifically with reference to examples of working with Aboriginal communities, Nicholls (2009, p. 120) explains how “Indigenous epistemologies and axiologies can inform the undertaking of participatory and collaborative research.” This is by taking into account that “the individual person is constituted through his or her communicative and interactive relations with others” (p. 121). Chilisa (2012) for her part notes the similarity between Maori arguments concerning the essential connectivity of people, who exist in relation, and the African concept of Ubuntu (see also ► [Chaps. 15, “Indigenist and Decolonizing Research Methodology,”](#) ► 87, “Kaupapa Māori Health Research,” ► 88, “Culturally Safe Research with Vulnerable Populations (Māori),” ► 89, “Using an Indigenist Framework for Decolonizing Health Promotion Research,” ► 90, “Engaging Aboriginal People in Research: Taking a Decolonizing Gaze,” and ► 97, “Indigenous Statistics”).

In this chapter, I offer some suggestions for how, in the conduct of focus groups, one can consciously inform the research in terms of an appreciation of Indigenous ways of knowing, where knowing is understood as a relational exercise. That is, I offer detail on how focus group facilitators can give due recognition to epistemological questions in the process of conducting research, while being alert to Indigenous ways of knowing.

2 Defining Some Contours of Indigenous Epistemologies

Considering Indigeneity in the context of Africa, Ossai (2010, p. 5) suggests that one of the prime qualities of Indigenous ways of knowing is that they are relevant to solving problems as identified in communities and they involve the community’s

participation in the knowledge-construction process. In order to spell out what “African Indigenous Knowledge Systems” (AIKS) can put forward as a viable alternative (or as an important complement) to “Western Scientific Knowledge,” Ossai points to several features of AIKS, which he contrasts with more Western-oriented styles of knowing as follows:

- Indigenous styles of knowing encapsulate intuition in the sense of intuiting connections, and therefore are more holistic than (Western-oriented) analytic and reductionist approaches.
- Oral story telling is paramount in this style of knowing, based on people exploring their stories (experiences) together.
- The way of creating/generating data is “slow/inconclusive” – in that it is stressed that experiences/data can be subjected to reformulation in the light of further experience and discussion around it. This is in some contrast to Western scientific approaches which he sees as fast and selective (for example, selecting specific factors which are isolated for attention).
- Indigenous knowing is more capable of taking into account long-term cycles of feedback, rather than being focused on short-term analyses. It is also less linear in its thinking – and does not try to link “effects” with particular causes in linear fashion.
- And lastly, it caters for the inexplicable (which can also be linked to the spiritual) – rather than trying to orient truth-seeking primarily in terms of what can supposedly be “scientifically” understood (Ossai 2010, p. 10)

Goduka (2012) compares these understandings of the processes of AIKS knowledge construction with Western-oriented epistemologies by focusing attention on the question of how truth-seeking as a collective enterprise is regarded in AIKS. She argues, along with other Indigenous-oriented authors, that what is specific about Indigenous modes of knowing is that they are *intentionally communally oriented*. As she puts it:

Communal knowledge ensures that knowledge is not collected and stored for personal power and ownership by individual specialists, but is rather developed, retained and shared within Indigenous groups for the benefit of the whole group. (Goduka, 2012, p. 5)

This conception of knowing as an expression of communal togetherness is also emphasized by Harris and Wasilewski (2004), in their setting out of what they see as an alternative worldview and attendant epistemology as offered by Indigeneity across the globe. They maintain that part of the strength of Indigenous cultural symbols (as they have described them) is that they can serve to create the groundwork for a “dynamically inclusive dialogic space.” This space, they note, “includes you, me, all of our relationships, taking place in our various personal, social, political, cultural, physical and spiritual contexts” (p. 494). They explain too that one of the characteristics of such a dialogue is that people appreciate that

our strength is increased by sharing [in the process of developing communal wisdom]. We can affirm our view, expand our view, or sometimes alter or even give up our current view when we encounter a new one. We can also allow others to have contrastive views as long as they do not impose their views on us and vice versa (p. 498).

Harris and Wasilewski's (2004) reference to not imposing views is set in a global context where they observe that thus far Western outlooks have become imposed as ways of knowing and living, to the detriment of more relational ways of knowing and problem-solving.

It is worth highlighting here that I am not claiming that this approach to knowing can be "found" in all Indigenous cultural heritages independently of the hermeneutic process of *interpreting the heritages*. As Hallen (2002, p. 66) points out in the context of Africa, the process of "identifying and reexamining Africa's Indigenous 'traditions'" is itself not free of an interpretation based on some values that are brought to bear. Serequeberhan (2000, p. 67) too argues that this involves actively "sifting through [various] legacies, retaining that which is alive, . . . [and] casting off that which is lethargic." This hermeneutic process is at the same time a call for regenerating what is considered to be valuable and alive – and worthy of nurturing – "in" the traditions (as located). This fits in with a constructivist position which recognizes that the interpretation of history and traditions is indeed a value-laden process, guided by an intention, in this case the intention to revitalize aspects of the heritages (see also Romm 1998, 2010, 2016; Magnat 2012; Lincoln and Guba 2013; Quan-Baffour and Romm 2015, for more detailed expositions of how the hermeneutic process of interpretation can be admitted.)

A question remains as to whether people who are not brought up within cultural heritages, where it is understood that the individual is inseparable from the community, can fully appreciate the flavor of epistemologies based on communal knowledge construction. This is the question of the translatability of paradigms, including epistemological ones. My position in this regard is that stances are not completely untranslatable and that points for comparison between them can be made, albeit that the terms used in talking "across" paradigms may still have different meanings/understandings associated with them, as people engage in conversation to enrich their appreciation of their possible meanings (cf. Flood and Romm 1997; Romm 1998, 2001, 2007, 2010, 2015; Hallen 2002; McIntyre-Mills 2000, 2014; Pollack 2006; Osei-Hwedie 2007; Denzin and Lincoln 2008; Midgley 2011; Cisneros and Hisijara 2013; Mertens et al. 2016). Chilisa (2012, p. 25) supports this stance when she suggests that her locating of an "Indigenous Research Paradigm" need and should not imply adopting "an either-or approach, where, in the discussion of "Euro-Western paradigms and postcolonial Indigenous paradigms, these paradigms become essentialized, compelling thought along binary opposites." Likewise, Nicholls (2009) mentions that she does not agree with a position which essentializes the difference between cultures and reinforces dichotomies between cultural groups.

What Nicholls (2009) proposes is that researchers involved in cross-cultural research should be alert to spaces of potential connections between themselves and participants (as played out in the research process). I suggest that this was attempted

in the case of the facilitation of the focus group discussed below, where I as White cofacilitator was involved (with other facilitators, White and Black) in facilitating focus group discussion with Black school teachers. In considering these racialized categorizations, I take the view, along with a myriad of other authors/actors that the categories Black and White are social constructions, which are nevertheless socially “real” in their consequences (see, for example, Kiguwa 2006, p. 113; Ansell 2007, p. 329; Romm 2010, pp. 10–13; Naidoo 2011, p. 628).

In the case discussed (as an illustrative example), I offer an account of an attempt to give credence to Indigenous epistemological orientations during the focus group session, by the facilitators expressing explicitly (albeit not in jargonized language) that the purpose of the discussion is to generate ideas collectively, as a process of being and learning together. As some authors advise (Gregory and Romm 2004; Dickson-Swift et al. 2006; Mapotse 2012; Romm et al. 2013; Austin 2015; Rajagopalan 2016), we also tried to blur the boundary between ourselves as “professional researchers” and the participants, by seeing ourselves as part of the community of teachers concerned with “making schools better” and by seeing the participants (lay researchers in this case) as part of the research process in which we all were involved in coexploring the issues. This intention resonates with Higginbottom and Liamputtong’s (2015, p. 4) delineation of a participatory approach, which is, *inter alia*, “multidirectional” and “may create new insights for the professional researcher[s] and the communities involved in the research.”

In offering their reflections around decolonized methodologies in cross-cultural research, Vannini and Gladue (2008, p. 141) consider that a sharing approach as adopted by researchers can express a heartfelt caring and is a way of admitting that the construction of realities (as understood) is relational. Through the example which I outline briefly in this chapter, I offer an instance of how we as facilitators became involved in the discussion to forward its development. But before I turn to this, I provide some background to my considerations around sensitivity to the notion of knowledge-making as a communal process, by engaging with some of the literature on focus group research as a methodology.

3 Some Literature on Focus Group Research and Lacunae Identified

It is specified in much of the literature on focus group research that the “data” that are developed via focus group discussion should be seen as being a product of the group interactions. For example, Hollander (2004, p. 362) expresses this understanding of focus group discussion as follows: “Participants in a focus group are not independent of each other, and the data collected from one participant cannot be considered separate from the social context in which it was collected.” Gray et al. (2007, p. 362) suggest that this should be considered as one of the strengths of focus group research. They explain: “Perhaps the most important benefit of focus groups is that the give-and-take among participants fosters reflection on other people’s ideas.” Claverling and McLaughlin (2007, p. 400), writing in the context of considering

qualitative health research, likewise suggest that “focus groups are an important element of qualitative health research, valued for the forms of knowledge and understanding that emerge from interactions among participants.” And Mkandawire-Valhmu and Stevens (2010, p. 684), in their account of what they call the “critical value of focus group discussions” (in their case in research with women living with HIV in Malawi), write up the research by choosing to “identify collective insights revealed in focus group interactions whereby participants reacted to and built on the experiences, interpretations, and evaluations of other participants” (p. 688).

Nevertheless, although many authors have pointed to the important function that focus groups can serve in aiding collective generation of insights (see Liamputtong 2011), most authors do not indicate how discussions *can be set up* so that participants can appreciate that collective researching of the topic(s) is what is being encouraged, as a process of people thinking together about the issues being raised (if this is the case). Nor it is common for authors to render explicit the orientation to “knowing/understanding” that facilitators may be adopting when orienting the discussion process. Hence, Farnsworth and Boon remark (2010, p. 605) that “plenty of attention has been paid to the development of the focus group as a research tool but, oddly, very little attention has been paid to the relational dynamics that are intrinsic to its use.”

There is thus arguably a dearth of literature on how the processes of interaction and relational dynamics in focus group discussions lead to the data that become generated via the discussions. And (linked to this), there is scant reference to how facilitators might pay attention to *epistemological issues concerning styles of knowing* that can be activated during the discussion and, more importantly for this chapter, on how *cultural sensitivity to knowing practices of participants* can be displayed. In this chapter, I suggest that to express sensitivity to Indigenous ways of knowing, facilitators need to find a way of alerting participants that the focus group session ideally involves a *process of being-in-relation as well as knowing-in-relation*. In other words, one can alert participants that the facilitators value cultural styles where coconstruction of views is a result of people feeling “in connection.” This would then fit in with the advocacy of decolonizing research as explicated by, for example, Chilisa (2012), Ndimande (2012), and Nicholls (2009), as discussed earlier.

Rodriguez et al. (2011) specifically raise the issue of cultural sensitivity as a concern that needs to be made more central in focus group research settings. With acknowledgment to the work of Morgan (2002), they make the point that although there is a large body of literature on focus groups, the goal when undertaking methodological reflections should also be to develop the focus group method in this direction. In trying to develop the method, they suggest that this can be done along the lines of “illuminating the importance of using culturally responsive research practices ... to guide qualitative methodology and, in particular, for focus group development” (Rodriguez et al. 2011, p. 401). Liamputtong (2008, 2010, 2011) similarly states, it is crucial for researchers facilitating (qualitative) research in cross-cultural contexts to exhibit culturally appropriate communication. These

arguments are applicable to the focus group session discussed below, where this was an issue that was tied to the possibility of defining “knowing” with reference to knowing practices which resonate with Indigenous traditions for communal coconstruction. This is also affirmed in Ndimande’s (2012) reflections on “decolonizing research.” Considering in particular the use of focus groups, Ndimande indicates that what he sees as important about the potential of focus group discussions, used in decolonizing fashion, is that “the emphasis on collective or group participation versus individual participation has stronger impact in the discussions” (2012, p. 216). He sees focus groups as able to encourage this emphasis.

4 An Illustrative Example: A Focus Group Session with Teachers in KwaZulu-Natal

In this section, I turn briefly to one of the focus groups conducted with teachers at a rural school in Estcourt, KwaZulu-Natal as part of a national project in South Africa (which took place from 2013 to 2015) entitled “Making Schools Better.” This project targeted 500 schools across five (out of nine) provinces in South Africa, with questionnaires and focus group sessions being employed as part of the research process. Forty-six researchers from the University of South Africa (Unisa) were involved in facilitating focus group discussions with subsampled schools (<http://www.unisa.ac.za/cedu/news/index.php/2015/12/500-schools-project-making-schools-better-closing-seminar/>).

In the exemplar discussed in this chapter, which involved focus group discussion with six teachers at the school, the facilitators used both mother tongue (isiZulu) and English (with different facilitators using different languages at various points in the discussion). We hoped to show respect for Indigenous cultural expressions through introducing the session in isiZulu. Also we believed that by introducing the session in mother tongue, the participants would recognize that they could feel free to speak the language with which they were most comfortable. They would presumably be aware that we were trying to give cognizance to their cultural styles of expressing themselves. In this respect, we concur with Colucci (2008, p. 244) that comoderators/facilitators “are essential in focus groups where the moderator has limited understanding of the language, habits, shared knowledge and beliefs of the group ... as it is likely to be in a great part of cross-cultural research.”

But besides this, it was important to make explicit the epistemological orientation that we were bringing to the session. Therefore, one of the isiZulu speakers on our facilitation team opened the discussions with reference to a piece in the field guide, part of which I had written (the part cited below). This was written to be used as an introduction to all the focus groups conducted during this project. The facilitator thus translated the relevant section of the guide, which gave guidance as follows:

Focus Group Interviews with Teachers

Introduction for facilitators to share with participants:

The purpose of the focus group sessions [in this research project] is to gather some information about the teaching and learning of various school subjects, which can become the basis for “making schools better.” The idea is that together we can explore issues connected with teaching and learning more fully. This will supplement some of the data that we have obtained from questionnaires that have been filled in by a large sample of teachers across five different provinces. This project is supported by the Department of Education [in South Africa]. Any information or ideas that you share with us will, however, remain confidential in that no one will know who has said what in any of our reports.

Please note that if you are feeling that you do not want to answer some of the questions asked when you hear them, you can mention this to us – we do not want you to feel under any pressure here. But your answers will be helpful to us to gain a better understanding of what we are asking you about. You also may learn by hearing our questions and thinking about your answers to them. And hopefully you will learn from one another too.

Following this introduction (which included all the facilitators introducing ourselves), we proceeded to ask the participants to introduce themselves in terms of what grades they were teaching; and thereafter we proceeded with asking questions, which included asking for suggestions for “making schools better.” The main questions that we asked had been pre-prepared for the purposes of comparing answers from the different focus groups across the whole research project; nevertheless, the style of conversation followed an informal style of discussion, as suggested also by Ndimande (2012) as appropriate for research with Indigenous participants. As he states:

The focus group, as part of research design [in the case of the research upon which he reports], was appropriate with Indigenous parents because it is a technique for interviewing that straddles the line between formal and informal interviewing . . . Thus, a focus group interview allows for an informal environment (p. 216).

As the discussion proceeded, we intermingled English with isiZulu (with the isiZulu-speaking facilitators being fluently bilingual), albeit that the talk was mainly in English and even when facilitators spoke in isiZulu, the teachers answered for the most part in English. This could be because the teachers were teaching English as a first additional language (FAL) at the school as one of the subjects, and they might have wished to show us that they were proficient in the language.

Space in this chapter does not permit any detail on how the discussion proceeded, but by way of example, I refer to a set of statements around the issue that was raised (by a Grade 4 Mathematics teacher) regarding the language transition that the learners had to go through when they reached Grade 4. In this grade,

English (instead of home language isiZulu in this case) became the medium of instruction for all subjects. He expressed concern that the transition was difficult for the learners. One of the other teachers then mentioned that: “English is allocated less time in Grade 3 and the Department [of Education] always sticks on the mother tongue in this phase, so we just visit English.” Another teacher added that the government’s Annual National Assessment (ANA) process does not concentrate on assessing English in this phase, which is one of the reasons why it becomes sidelined. As she put it: “It is because we are afraid of ANA and we don’t like our school to be named as belonging to the ones that have done very badly so this is why we always do isiZulu and Mathematics most of the time and just visit English and life skills because they [the learners] are examined on that which is isiZulu and Mathematics.”

I then asked – in relation to the Maths teacher’s original statement of concern – “And do you think the learners are being prepared for making the change over to the language of instruction which is English later on?” One of the teachers stated: “Yes we try our best.” One of the facilitators (isiZulu mother tongue, but speaking English here) followed this up: “But mam [some of] you just said you just visit English, do you think when the learners reach Grade 4 . . . when are they supposed to do everything in English, are they prepared?” The teacher replied that “They are not really.” And another teacher reiterated that it became problematic because “they are expected [to do] all the subjects in English.” At this juncture, I asked: “And what could be a solution to that?”

The conversation went on by participants expressing that the problem should not be addressed by merely looking at the challenge of English on the part of learners; the problem was more widely that learners were not exposed to an adequate amount of reading matter in either isiZulu or English. There was no library for them and problems arose because learners were not doing much reading. Some suggested that a solution to this could be that newspapers and other material could be used to supplement the dearth of reading matter. Others used the opportunity to indicate to us that the lack of reading material is a matter that needed to be relayed to the government as they needed support in this regard. This concern (along with others) was again expressed by this group when we organized our “member checking” visit to the school a few months later. Their expressions of concern on this matter, which were echoed by many teachers and learners across the various provinces, and which we discussed with government officials in the Research division of the Department of Basic Education (DBE), could have been a contributing factor which led to a government program of providing readers in the 11 official languages to supplement the government provision of workbooks. As noted by Minkler (2010, p. 85, citing Guthrie et al. 2006), “most policy work involves multiple players ‘hitting’ numerous leverage points. In this complex system, it is difficult to sort out the distinct effect of any individual player or any single activity.”

Meanwhile, returning to the focus group itself, as had been specified in the focus group field guide for all facilitators, toward the end of the session we requested feedback from participants regarding their experience of the session. I stated this request as follows: “We are interested to know how you experienced the discussion

today. How did you feel about talking with us? And would you want to raise any other questions?"

A few of the participants indicated that they were happy that we had been there as they enjoyed the refreshments that we had brought along (biscuits, nuts, and fruit juice). Others laughed and said that these had been good. Although this may seem an unimportant feedback, it lends substance to Liangputtong's (2011, p. 139) statement that "the sharing of food . . . is an essential part of conducting focus groups in cross-cultural settings." She gives examples of research with Latina women, Emirati women, immigrant participants in Canada, Aboriginal communities, Mexican migrant farmworkers, and Pacific Northwest Indian communities. The food given in our case (which for us was a sign of respect for their time and a way of offering something immediately concrete in return) was clearly also significant to these participants. We later presented them all with Unisa-logo'd pens, which were also well received.

Having heard their feedback regarding the value of the refreshments that we had brought, I then asked: "Do you think you learned something from hearing each other talk?" To this, certain participants said "yes" and I asked if they could offer some examples. One teacher stated that she had learned about group teaching as being a strategy that the DBE advises (dividing up the class into groups and spending some time with one before moving to the next and hoping that the first groups will keep themselves busy). But, she said that in a class of 48 people, it is chaos. Another participant added that even when they mention to the District officials that this advice is impractical, they are told to "keep trying." Various participants echoed this frustration with the way the advice is given, while they also found somewhat amusing – and perhaps cathartic – the manner in which their colleagues were expressing to us about their being told repeatedly to "keep trying." In this way, they were collectively coconstructing the experience of frustration at the attitude that they were seeing in the injunction for them to continue trying against all odds. This was one of the other issues that we mentioned in our report that we subsequently shared with government officials in the Research division of the DBE, as part of our effort to engender further research dialogues.

One of the other facilitators in the focus group feedback session then asked: "Do you sometimes sit together and discuss problems that you have at school?" They answered in chorus: "Yes." He asked: "What makes this session different from discussing amongst yourselves?" One of the teachers answered: "It is nearly the same." I summarized: "So it is not very different from your talking here today with us being here?" And another replied: "It is like our normal way of talking together." Another stated: "But the answers that we give when we discuss together are different." When I asked how this was so, she said that when we were there the answers involved more what could be done within the system to support them, for instance, in terms of workshops for teachers that could be set up – including how to introduce inclusive educational teaching strategies so that all children could be catered for, especially in large classes.

What is important in relation to the argument in this chapter is that the teachers did not feel that the process of discussion in the focus group session – that is, of

sharing ideas and thinking together – was different in terms of process from their “normal,” that is, culturally familiar, style of interacting. They remarked merely that the content in terms of thinking about how they might harness support from “the system” differed somewhat from their usual meetings together. It can thus be said that they experienced the discussion with our being there as involving a similar style of conversation that they normally practice, which involves seeking together “answers” to experienced problems. This implies that the form of inquiry as used in the focus group resonated with what Ndimande (2012, p. 223) calls “cultural epistemologies.” That is, the participants did not feel that the facilitators brought in a culturally unfamiliar mode of developing understanding as a collective enterprise. Whether our use of their Indigenous language to open the discussion helped in this regard is difficult to say, especially that the participants themselves chose to switch to English most of the time. But what can be said is that the beginning introduction at least set the tone for what Ndimande calls an informal conversation (p. 216), where people participated in being-in-relation with one another toward knowledge-construction/collective inquiry.

What is also worth highlighting is that participants often used the collective “we” in their way of speaking, as, for example, in the set of statements referred to above – where one of the participants indicated that “we don’t like our school to be named as belonging to the ones that have done very badly,” and another stated in relation to learner preparedness in English that “we try our best.” Also, in their recounting their experience of frustration with subject advisors who address them as if they are not trying hard enough to manage the group work in classes, the collective “we” was used by participants.

Mkandawire-Valhmu and Stevens (2010, p. 688) likewise favorably report that in the focus group sessions that they organized with women living with HIV in Malawi, “the collective *we* was frequently used in their explanations and responses to each other.” They see this as a sign that the focus group discussion was a forum for collective generation of insight as well as a forum for activating feelings of togetherness.

5 Conclusion and Future Directions

In this chapter, I have explored possibilities for conducting focus groups underpinned by an Indigenous-oriented epistemological position which does not consider individuals (individual selves) as being the route to knowledge production, but sees knowledge-construction as a relational process of developing insights (which are linked to practical ways of living). I pointed to lacunae generally in the literature regarding efforts of facilitators to pay attention to epistemological issues and more particularly regarding efforts to orient focus group discussion to take into account Indigenous styles of knowing. Although the example I used in this chapter is situated within education, many of the issues I have discussed can be applicable to any other health and social issues within the health social sciences.

In view hereof, I would suggest that especially when focus group research is being conducted with Indigenous participants, an endeavor should be made to introduce the sessions in a way that indicates that relational styles of knowing are being encouraged. Without having to use jargon such as “epistemology,” “relational thinking,” and so on, facilitators can still find ways of indicating that they are not gearing the research to replicating “dominant” (Western-oriented) styles of knowing. I would suggest that culturally attentive researchers can experiment with types of “introductions” that signal this; they can in turn seek feedback from participants later in order to see how their storylines about, and attempts to encourage, relational ways of knowing which are familiar to participants have been received.

In this way, more case material on possibilities for disrupting the (sole) legitimacy of dominant styles of knowing can be developed. With reference to such case material, researchers can make comparisons between different experiences of attempting to foreground epistemological questions as part of the research process, also considering participant feedback (and exact expressions of participants) in relation to this. I have left partly in abeyance the issue of language use and how this might be handled when organizing cross-cultural research. But, Austin (2015, p. 25) reminds us that when the nurturing of “relationship” (as in a relational axiology) is given primacy by researchers, it needs to be borne in mind that “there may be differences in comfort level with the language used for the research, which needs to be recognized and addressed.” Apart from this issue, I have suggested that it is important to find ways of signaling to participants that relational styles of knowing are being encouraged.

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Visual Depictions of Refugee Camps: (De) constructing Notions of Refugee-ness? 104

Caroline Lenette

Contents

1	Introduction	1812
2	Why Discuss the “Visual”?	1814
3	Visual Depictions of Refugee Camps	1816
4	Humanitarian Sentimentalism	1816
5	Visual Analysis Process	1818
5.1	Tropes Emphasized	1818
6	Adding to Kurasawa’s Framework: Feminization, Childhood, and Criminalization	1822
6.1	Feminization	1822
6.2	Childhood	1823
6.3	Criminalization	1824
7	Conclusion and Future Directions	1826
	References	1827

Abstract

Visual representations of asylum seekers and refugees in precarious situations can have a significant impact on how such individuals are imagined in politically stable contexts, particularly in Western nations. Visual methodologies are relatively underused to examine how notions of refugee-ness are constructed and perpetuated to shape public opinion about asylum seekers and refugees. This topic is of particular relevance considering the intense media coverage of the recent and continuing Syrian refugee crisis in Europe during 2015–2016, and the abundance of images about this humanitarian catastrophe. Using refugee camps as example, I apply Kurasawa’s framework of “humanitarian sentimentalism” where he describes four typifications (or tropes) associated with images of

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humanitarian crises (Personification, Massification, Care, and Rescue) to visual depictions of refugee camps. This process of categorization of themes highlights what is emphasized for viewers in such imagery. As part of a broader *reflective* approach, I also discuss the themes of Feminization, Childhood, and Criminalization as key conventions in visual representations of asylum seekers and refugees. While there are ongoing tensions in relation to visual representations of people in precarious situations, visual methodologies can provide a rich dimension to critical discussions on complex and multifaceted issues.

Keywords

Visual representations · Asylum seekers · Refugees · Visual analysis · Refugee camps

1 Introduction

Images can shape and convey specific understandings of global events in the imagination of viewers, particular among Western audiences. Amidst the largely chaotic circumstances that characterize different stages of refugee-ness, photographs are often used to convey the precariousness, misery, and urgency that asylum seekers and refugees can experience. The United Nations High Commissioner for Refugees [UNHCR] (2017) estimates that there were approximately 22 million refugees at the end of 2016. The most *visible* humanitarian crisis occurring in the world in 2015 and 2016 was the global movement of asylum seekers and refugees from Syria and northern Africa as they attempted to reach European countries. This situation received intense media coverage and a number of images have been used to convey the urgency and precariousness of Syrian refugees (see Lenette and Cleland 2016). Indeed, visibility is crucial to denouncing injustices and chaos (Szörényi 2006), and visual means are often used to trigger pity or sympathy among Western audiences (Kurasawa 2013). Some images have been instrumental in shaping the world's understanding of crisis situations, and indeed in *changing* it. For example, the notorious photograph of Phan Thi Kim Phuc, the 9-year-old Vietnamese girl running from her village after being severely burnt in a napalm attack, conveyed the horrors of the Vietnam War in a powerful way, adding to pressures on political leaders to end the conflict. Closer to our times, photographs of 3-year-old Syrian Aylan Kurdi, who drowned while crossing the Mediterranean Sea with his family in September 2015, and whose body washed up on a Turkish shore, was influential in urging nations to act in the face of the major refugee crisis unfolding (Lenette 2016).

Even when situations of humanitarian crises do not make front-page news, key actors such as international nongovernment organizations, humanitarian agencies, and Western media outlets have continued to use images as a strategy “deployed to break through numbing conditions of denial” (Haaken and O’Neill 2014, p. 82). For instance, dominant visual depictions of refugee children usually show emaciated and sad-eyed African infants requiring urgent medical care, to mobilize donations from audiences in Western countries (Malkki 2015; Thompson and Weaver 2014).

Photographs can hence contribute to how viewers imagine refugees with implicit and explicit aims of triggering compassion or empathy (Haaken and O'Neill 2014). Visual depictions of asylum seeking and refugee situations are assumed to convey a certain reality, but by doing so, tend to shape viewers' ability to "imagine" refugees as distant and threatening (Johnson 2011). The outcome tends to be that the distance between viewers (usually from Western nations) and those depicted in photographs is reinforced. Such photographs tend to "produce spectacle rather than empathy" (Szörényi 2006, p. 24) and contribute to induce fear by further dehumanizing refugees, rather than challenging conservative political rhetoric and sociopolitical disparities at the source of forced migration (Kurasawa 2013).

Negative notions linked to asylum seekers and refugees through imagery remain a dominant theme in the literature. Bleiker et al.'s (2014) analysis of how asylum seekers were visually portrayed in front-page news in two prominent Australian newspapers highlight the potency of visual imagery in producing problematic constructs about refugees and asylum seekers in the media, which, when combined with deep-seated ideas of state sovereignty, border security, and national identity, create a culture of *inhospitality*. As a result, a sense of moral panic (Martin 2015) can arise in the nation's psyche, where "[f]ear of strangers outweighs the moral obligation to help them" (Bleiker et al. 2014, p. 192). Furthermore, photographic collections like the UNHCR online repository that document various refugee situations emphasize a particular "image" of refugees as victimized, depoliticized, and female (Johnson 2011; see also Malkki 1996; Haaken and O'Neill 2014). Therefore, it is useful to refer to what Christmann (2008) describes as a photographic *reality* conveyed in a two-dimensional format as one among many ways of considering a person, place, or event. In this chapter, my concern is precisely to explore the photographic realities and discourses in four images used by the UNHCR to convey the circumstances of refugees living in camps to the rest of the world.

While the focus of visual representations tends to be on negative aspects linked to refugee-ness, scant discussions on "positive" imagery linked to refugees can contribute (albeit modestly) counternarratives to dominant visual discourses (Gilligan and Marley 2010). Yet, it is fairly unusual to come across visual depictions of refugee camps, in particular, that convey more positive aspects linked to resilience, livelihood, and community (see one example in Lenette 2016). Furthermore, in the United Kingdom, for instance, positive portrayals of refugees in the media tend to focus on their artistic contributions; apart from that, meaningful contributions in socioeconomic terms, for instance, are largely ignored or overlooked (Gilligan and Marley 2010). This trend perhaps signifies an inability to recognize the vast contributions that refugees make to a nation's socioeconomic welfare. Conversely, promoting positive images solely can also "sugar-coat" the complexities of refugees' realities and project a narrow understanding of the myriad of issues they may face in conflict situations, exile, as well as in resettlement. Indeed, Gilligan and Marley (2010) caution against focusing on talented and exceptional individuals solely and instead, argue that visual representations should convey the full intricacies of refugees' lived realities.

To this end, I use Kurasawa's (2013) framework of "humanitarian sentimentalism" and his four typifications (or tropes), namely Personification, Massification, Care, and Rescue to determine which dominant tropes appear in four selected photographs. I use this approach to look beyond the surface and highlight what themes can be emphasized in such visual representations. My concern is to show how viewers can internalize specific ideas about asylum seekers and refugees (consciously and unconsciously) through visuals, and the potential for these set ideas to perpetuate public perceptions – in Western nations but also more broadly – of asylum seekers and refugees, and of forced migration situations in general. It is not my intent here to simplify complex and intricate depictions by using categories to analyze them. Rather, I would like to highlight how notions of refugee-ness can be constructed and reinforced through wide dissemination of visual patterns.

This analysis builds on my earlier work using Collier's (2004) "open viewing" to consider media images depicting asylum seekers in 2015 (Lenette and Cleland 2016), as well as discussions on an iconographic-iconologic approach to analyzing refugee photography (Lenette 2016). The "open viewing" approach is most useful at the initial stages of visual analysis where viewers let any impression emerge without rushing to find meaning or categorize. Following on from that, the iconographic-iconologic framework offers a *technical* or systematic way of "reading" photos by following a series of questions. Kurasawa's framework of using four tropes on the other hand offers a *conceptual* way of "categorizing" photos, and as such, Kurasawa's approach enriches my application of the iconographic-iconologic framework to visual representations of asylum seekers and refugees. I argue here that a broader *reflective* approach, starting with a technical description through to conceptualizing key themes represented, is most useful in the visual analysis process. A reflective approach effectively combines technical and conceptual lenses to enable the emergence of richer themes.

2 Why Discuss the "Visual"?

My interest in analyzing visual representations of asylum seekers and refugees stems from a decade-long research program using visual ethnography. Having used photo-elicitation, photovoice, and digital storytelling in collaborative research with refugee women (Lenette and Boddy 2013; Lenette et al. 2013), I began paying more attention to how the Australian media in particular portrayed stories about asylum seekers and refugees using visual means in a distinctively polemic context. The abundance of refugee photographs globally and nationally means that audiences are constantly bombarded with visual narratives on the topic, most reinforcing or justifying draconian policy measures under the banner of "security" and "sovereignty." In recent times, I have developed a particular interest in understanding how visual-based research methods can be used to influence policy directions. I have

begun teaching undergraduate students how we imagine asylum seekers and refugees based on visual narratives that dominate our everyday lives, and how these constructs shape public opinion and government policy. At first, students struggle to understand the links between visual representations and policy, but once they do, wonderful insights emerge in class.

The intense media attention to the Syrian refugee crisis in Europe which peaked in 2015 has triggered more robust discussions about how images of asylum seekers and refugees are disseminated and used to influence policy and decision-making. The photographs of Aylan Kurdi's lifeless body, broadcast around the world, shocked audiences with the human tragedy of an issue long presented to the public with little humanitarian consideration. As the images became symbolic of the European refugee crisis, a number of policy measures emerged to address this precarious situation; Germany in particular showed leadership by urging nations to allow asylum seekers in dire circumstances to cross borders as they sought safety. Concurrently, the Ethical Journalism Network's *International Review of How Media Cover Migration* (2015) was released, highlighting the narrow focus of media coverage of refugee and asylum seeker issues, and recommending a broader lens for coverage of these issues, considering the media's strong influence on shaping understandings of and responses to refugee issues. Ethical Journalism Network (2015, p. 7) stated: "The inescapable conclusion is that there has never been a greater need for useful and reliable intelligence on the complexities of migration and for media coverage to be informed, accurate and laced with humanity."

In that same year, I set out to write critical commentaries on different 'forms' of visual representations of asylum seekers and refugees to add to emerging discussions on this topic. Some examples include: analyzing extant photographs using an iconographic-iconologic approach (Lenette 2016), the media's use of asylum seeker photography in times of crisis (Lenette and Cleland 2016), visual depictions of refugee deaths at border crossings (Lenette and Miskovic 2016), media representations of asylum seekers and refugees in Australian regional press (Cooper et al. 2016), international media coverage of key events linked to asylum seekers in the Australian context (Laney et al. 2016), or themes in drawings created by children living in Australian detention centers (Lenette et al. 2017). Like McDonald (forthcoming), a disabilities scholar examining visual representations of disability in art, I must admit that I was a passive viewer myself for many years and "I simply gazed and moved on." But since I turned my attention to the sociopolitical constructs conveyed in visual depictions of asylum seekers and refugees, I have become passionate about highlighting the need for a more critical stance on how such visual representations are used to influence public opinion and reinforce political rhetoric. Just like Malkki (2015), I reiterate Foucault's (1988, p. 154) definition of criticism as "pointing out on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practices that we accept rest," and this is what this chapter attempts to achieve.

3 Visual Depictions of Refugee Camps

The analytical focus of refugee photography currently lies in the field of media and journalism, and explores how photographs can be used to manipulate public perceptions of asylum seekers and refugees. For instance, a systematic review of visual patterns associated with refugee photography in two major Australian national newspapers when refugee issues were at the peak of political debate revealed that images were used to reinforce detrimental and fear-mongering public discourses, ultimately depersonalizing and dehumanizing refugees (Bleiker et al. 2013; see also Esses et al. 2013). Gilligan and Marley (2010) concur that the image of the “overcrowded boat” is common and probably the most negative trope used in media representations of asylum seeking as threat-to-the-west. But the conceptualization of asylum seekers and refugees as “threatening” begins *well before* they (attempt to) reach a Western nation’s borders. More precisely, visual constructs linked to refugee camps also play a key role in shaping the nation’s perception of asylum seekers and refugees.

Refugee camps are said to be “the only place for people who don’t fit in with our image of the world” (Møller 2015, p. 134) and are increasingly becoming the norm (Bulley 2014). Such camps have been theorized as “non-places” where “refugees are reduced to a bare form of life that merely maintains and manages their raw biological existence” (Bulley 2014, p. 65). There is an abundance of literature detailing poor living conditions in refugee camps (Malkki 1995, 2015; Agier 2011; Ramadan 2013; Bulley 2014), ones that generally fail to meet an adequate standard to provide “spaces of security for individuals and communities at their most vulnerable” (Bulley 2014, p. 63). Yet, when it comes to visual representations of refugee camps, such imagery does not necessarily speak to the vulnerability of refugees. Instead, the inherent assumption that refugees are “unlawful” (Bleiker et al. 2013, 2014) rather than vulnerable is more likely to shape viewer responses to photos of refugee camps. For instance, images of refugees living in inhospitable conditions can convey strong connotations of poverty and low socioeconomic status, which can also be associated with risk factors leading to deviancy and criminal behavior (Gabbidon and Greene 2005). This assumption would then create a different notion of the “imagined refugee” in the minds of Western viewers in particular, highlighting the importance of looking at images used by agencies like the UNHCR to portray refugee camps.

4 Humanitarian Sentimentalism

Kurasawa (2013, p. 202) argues that there is a sense of “humanitarian sentimentalism” created through the use of pictures to convey suffering and precarious situations linked to forced migration and displacement, which refers to:

a set of narratively and visually based mechanisms aiming to trigger feelings of sympathy, repugnance, pity, and nobleness amongst Northern audiences toward subjects represented as

victims whose suffering is directly attributable to events constituted as humanitarian catastrophes in the global South.

The framework of humanitarian sentimentalism as outlined in Kurasawa's description of four "tropes" or iconographic conventions is based on major visual typifications of crises used systematically mainly by international nongovernment organizations and Western media. Each trope or convention of Personification, Massification, Care, and Rescue aims to elicit the respective moral sentiments or qualities of "pity (sorrow toward the state of victims); repugnance (revulsion or guilt toward the conditions of victims); nobleness (greatness of character directed at saving victims); and sympathy (compassion toward the suffering of victims)" (p. 206):

- i. **Personification (evokes pity):** This convention involves representing a single victim (or a very small group of people) in a state of distress to emphasize their vulnerability and precariousness; the typically close-up nature of such depictions conveys a sense of isolation that magnifies the person's suffering, and by doing so, usually provides a decontextualized narrative of the issue.
- ii. **Massification (evokes repugnance):** In contrast with Personification, people in situations of upheaval or displacement are represented in large groups or "en masse" to emphasize the magnitude of the crisis, resulting in a dehumanizing and depersonalizing effect; as such, subjective narratives are not privileged.
- iii. **Rescue (evokes nobleness):** This convention portrays an unequal rescuer-"victim" dynamic, with the "rescuer (almost invariably a white Westerner) being the only one in the frame granted the agency to intervene to transcend the deadly or unjust circumstances under which dwell those needing to be rescued (almost invariably poor non-Westerners of color)" (p. 208). This contributes to a passive or deficit-focused image of individuals at the center of crises, and the viewer is reassured that humanitarian agencies are fulfilling their roles.
- iv. **Care (evokes sympathy):** Unlike the relatively unequal and "heroic" dynamic inherent in the Rescue convention, the interpersonal and intersubjective nature of relationships between humanitarian actors and "victims" is more apparent; humanitarian involvement is based on an ethic of concern and care and a moral obligation to privilege the well-being and recovery of individuals.

These conventions have dominated visual imagery due to the need to convey the circumstances of those affected by disasters, humanitarian crises, and forced migration to mostly Western audiences, by translating "their suffering in ways that are comprehensible to such viewers because they correspond to familiar or typical interpretive patterns" (p. 207). Kurasawa acknowledges that, despite these conventions' capacity to elicit emotive responses from Western viewers, sociopolitical contexts and dominant policy approaches at the cores of such situations remain largely unchallenged. Importantly, similar themes as described in Kurasawa's work are explored in recent literature on visual representations of refugees and asylum seekers (see Szörényi 2006; Johnson 2011; Bleiker et al. 2013; Lenette 2016; Lenette

and Cleland 2016), making Kurasawa's framework particularly relevant to cross-cultural analyses of constructions of refugee-ness.

5 Visual Analysis Process

World Refugee Day is celebrated each year on 20 June. In 2015, the UNHCR website featured a story entitled *Ending the second exile* to highlight the precarious situations of refugee groups around the globe. The story featured a series of photographs taken for the UNHCR and illustrating refugee situations in different settings (Figs. 1, 2, 3, and 4). I used Kurasawa's framework of humanitarian sentimentalism to identify which trope(s) described above was/were represented predominantly in these figures.

5.1 Tropes Emphasized

5.1.1 Massification

Massification: In Fig. 1, the panoramic shot of a large number of refugee tents firmly lined up into the distance conveys a sense of endlessness and permanency to the issue. The caption contributes to the notion that this is a long-term and ongoing situation, referring to the setup of Dadaab refugee camp in 1991, the growth from an initial 90,000 to 325,000 refugees in 2014, and its status as the world's largest refugee camp. The barren nature of the surrounds adds to the "distance" of the



Fig. 1 Dadaab refugee camp (Source: UNHCR 2015)

situation as a context that would be largely foreign to Western viewers. While there are individuals in the foreground (who look like children), no connection is made possible with the viewer as their features are indistinguishable and their stories remain unknown. The cloudy background adds to the harshness and gloom of the setting.



Fig. 2 Ban Mai Nai Soi refugee camp (Source: UNHCR 2015)



Fig. 3 Chad refugee camp in Iriba (Source: UNHCR 2015)



Fig. 4 Dollo Ado camp (Source: UNHCR 2015)

Rescue: The prominence of the UNHCR name and logo on the side of most tents (the unmistakable blue letters on a white tarpaulin background) conveys the organization's mandate, or more specifically, its mission to "save" vulnerable individuals by providing them with shelter and basic needs while they live in exile. The framing of the photograph ensures that the organization's presence and role in the camp is acknowledged, so that Western viewers can witness the intervention from the comfort of their homelands.

5.1.2 Personification

Personification: In Fig. 2, the close-up depiction of two women and a child in a small dwelling with basic amenities in a Thai refugee camp is presented with a narrative of intergenerational refugee-ness. Through the captions, the state of uncertainty linked to refugee camps is juxtaposed with the story of the older woman, Baw Meh, a Burmese refugee for 18 years, and the mother and grandmother of the other persons captured in the photograph. The framing emphasizes the modest and cramped living conditions: the women are squatting and sitting on the floor, and the cooking takes place over a naked flame. The women's traits are identifiable, and we learn Baw Meh's name, making them more relatable. The woman at the center of the photograph is depicted performing the traditionally female role of cooking. There is no adult male figure in the photograph, which may suggest that the women are alone to care for the child. Importantly, there is no indication of the sociopolitical factors in Myanmar that resulted in this family living in a refugee camp in Thailand.

Care: While less evident here (in relation to Kurasawa's definition), the trio is intentionally depicted as a family in the same space and engaged in a mundane activity. This may convey the impression that they are cared for and safe in this refugee camp, and that despite the conditions in which they live, they are together. The humble camp living conditions though dominate the photograph.

5.1.3 Massification

Massification: As in Fig. 2, the focus in Fig. 3 is on a small group of refugee women. However, none of the women are named and we do not know anything about their relationships, except that they are all Sudanese. The women are not identifiable and the effect is rather depersonalizing. They are pictured sitting on the ground in bare surroundings with clothes hanging in the background, with no real sense of what they are doing. The caption suggests boredom because of lack of opportunity to undertake paid work. One woman bows down her head, and all of the women wear scarves over their heads and around their faces, adding to the space between viewers and those depicted. The overall impression is deficit-oriented and suggests that they are passive actors in this setting. The brown and bare landscape extends into the distance, suggesting a lack of infrastructure in the immediate vicinity. Although the women are wearing colorful clothes, the overall impression of the photograph is that it is quite gloomy.

5.1.4 Personification

Personification: In Fig. 4, the smiling faces of the woman and child in the foreground, as well as the solar lamp, are the focal points of the photograph. The woman is named as Kadija; the caption establishes that the children are hers and that they are Somali refugees. Their traits are distinguishable, and Kadija looks straight at the camera (and by extension, at the viewer). Her posture is different to that of the women portrayed in Fig. 3, and suggests a sense of confidence. The setting is identified as *her* house, which also points to agency. In contrast with the gloomy undertones in Figs. 1, 2, and 3, the light enhances Kadija's bright and colorful clothing.

Rescue: While in the background, the blue UNHCR name and logo on a white background is still discernable. The framing of the photograph ensures that there is a constant reminder of the organization's presence and role in supporting refugees in camps. Kadija is depicted alone with her four children; perhaps she is a sole parent or the lack of a presence of an adult male figure is intentional. Either way, the framing of the photograph suggests her vulnerability as a sole carer of four, with the UNHCR (literally) watching over her.

Care: The caption refers to Ikea, a large multinational retail company popular in Western countries for its designs and ready-to-assemble furniture, and a philanthropic partner of UNICEF. The reference suggests that a highly profitable company on the other side of the world shows concern for vulnerable families in precarious situations. Solar lamps are particularly vital for women and young children who are more at risk of assaults in camps, particularly at nightfall; ownership of a lamp in this setting can mean the difference between safety and risk.

6 Adding to Kurasawa's Framework: Feminization, Childhood, and Criminalization

My ongoing work on the topic of visual representations of asylum seekers and refugees and their influence on public opinion and policy highlights three other important dimensions or key themes that can complement Kurasawa's framework, namely Feminization (represented in Figs. 2, 3, and 4), Childhood (represented in Figs. 1, 2, and 4), and Criminalization (represented in Fig. 1).

6.1 Feminization

Over the past few decades, the UNHCR and other international humanitarian organizations' visual rhetoric has adopted an approach of victimization, feminization, and racialization whereby "the image of a third world mother and child are emblematic of the refugee" (Johnson 2011, p. 1032). Images of women, strategically utilized by aid agencies in particular to trigger empathy and mobilize donations from Western audiences, tend to convey a lack of political agency and a sense of powerlessness. Bleiker et al. (2014, p. 194) explain:

Women are typecast as emotionally fragile and vulnerable, as helpless and needy. They are passive and powerless, overwhelmed by the circumstances surrounding them. Women and their social roles become frozen into a stereotypical pattern of familial duties combined with a sense of passivity and dependence upon others for rescue and survival.

This is particularly apparent in Fig. 3, but also evident in Figs. 2 and 4. In relation to this theme, Wright (2002) suggests that dominant depictions of refugees such as those serve to reinforce stereotypes based on Christian iconography, with the aim of stimulating empathy or responses among Western viewers using "familiar" imagery (see also Malkki 2015). Besides the theme of "exodus" replicated in depictions of mass migration and forced displacement, the recurring "Madonna and child" pose is increasingly used to convey vulnerability and precariousness through images of starving mothers with young children. In fact, Johnson (2011, p. 1032) explains that "the frequently used phrase 'refugee women and children' collapses the two groups into one undifferentiated whole. The cliché *womenandchildren* (...) serves to identify men as the norm, to reiterate the notion that women are family members." The abundance of images depicting refugee women and "womenandchildren" is problematic (A Google Images search using the terms "refugee woman" will often result in photographs of women holding children predominantly.), because it reinforces the ingrained "colonial attitudes toward the developing world" (Bleiker et al. 2014, p. 194) that perpetuate stereotypical gender roles, and produces unagentic ideas about refugee women.

What these points also suggest is that the theme of Feminization can easily be overshadowed by notions of Massification and Rescue, despite the widespread use of images of women (alone or more commonly with children) to represent notions of



Fig. 5 Feminization. Refugee women in a refugee camp in Sudan (Source: Australian Broadcasting Corporation 2012)

asylum seeking and refugee-ness. I argue that Feminization, due to its increasing prevalence, should in fact be considered as a stand-alone convention or trope. Considering the growing number of women in forced migration statistics worldwide (where numbers are often lumped together as “women and children,” see UNHCR 2013), a gendered lens should be integral to visual analysis of depictions of asylum seekers and refugees. Not in a simplistic and problematic manner as critiqued by Bleiker et al. (2014), but using a critical and intersectional approach (Lenette et al. 2013) that identifies how – and which part(s) of – women’s identities are purposely utilized, and when they are conveniently *ignored* (Fig. 5).

6.2 Childhood

I draw here on the important work of Malkki (2015) on figurations of the child and the infantilization of humanitarian work, and how this appeals to Western audiences. Images of children as representations of humanity as a whole have long been used to raise concern and compassion among donor countries (Wright 2002; Johnson 2011; Thompson and Weaver 2014), and to shape conceptualizations of migration in public discourse (Anderson 2012). Malkki (2015, p. 79) explains that the “child is often made to appear as the exemplary human, and as politically harmless and neutral – the most neutral of neutrals, *hors combat*” and as such, in the Western imagination at least, is considered as “a potent ritual and political actor in war zones and genocides.” The author argues that visual representations of children are most effective when they are used “(1) as embodiments of a basic human goodness and innocence,



Fig. 6 Childhood. A Syrian refugee child in a camp in Erbil, Iraq (Source: Itv plc (UK) 2015)

(2) as sufferers, (3) as seers of truth, (4) as ambassadors of peace (and symbols of world harmony), and (5) as embodiments of the future” (Malkki 2015, p. 80).

In Fig. 1, children are standing in the foreground but their traits are unidentifiable; however, we still perceive a notion of suffering because of the bleak surrounds. In Fig. 2, most of the child’s face has been intentionally left out of the photograph, perhaps to respect his privacy. However, his “absence” is even more potent as a representation of goodness and innocence; his identity as the grandchild not only emphasizes the intergenerational nature of the refugee status, but also symbolizes looking towards the future, with perhaps hopes for a different situation for him. In Fig. 4, the children are smiling and embody all the conventions outlined by Malkki above. As such, the inclusion of children as representatives of humanitarian concern and intervention is likely to remain a prominent form of dissemination using visuals particularly among Western audiences (Fig. 6).

6.3 Criminalization

Criminalization of asylum seekers and refugees (see Morrison 2001; Fábos and Kibreab 2007; Møller 2015) has emerged as a theme in the literature due to popular skepticism as to the motives of individuals seeking refuge, paired with nations’ fear over potential risks or burdens that meeting international obligations would entail. Concern regarding the “influx” of refugees and threats to national security through terrorism (Esses et al. 2013; Milton et al. 2013) has grown to such degree across the globe that it has given rise to a moral panic over the issue. One of the reasons for this trend is that conditions in refugee camps are deemed as similar to those of a prison environment, characterized by the presence of fences, surveillance towers, and ominous boundaries to convey a notion of refugees as illegal, threatening, and unlawful (Bleiker et al. 2013; Milton et al. 2013). Discussions of refugees as

“enemies at the gates” of Western nations, as Esses et al. (2013, p. 519) suggest, further emphasize the separation established between the viewer and the “victim.” Moreover, limited information on immigration detention centers like in Australia, for instance, also convey living conditions, layouts, and structures akin to prisons, with “extensive security and monitoring measures, and the omnipresent surveillance features, including high wire and razor wire fences, [and] surveillance cameras” (Coffey et al. 2010, p. 2073; see also Zion et al. 2010).

This consideration is further reinforced in observations likening the structured layout of refugee tents in a camp to a prison dorm, conjuring ideas of criminality, threat, and risk. Often, boundaries and observation buildings similar to the exterior façade of a prison are prominent in camp images; refugees are presented as being justifiably confined in settings similar to low security prisons. The layout and concentration of refugee camp accommodation alludes to high intensity accommodation in a small space, giving rise to an environment likely to foster conflict (Gaes 1985). Furthermore, the erroneous belief that ethnic minorities are commonly perceived as more susceptible to criminality (Gabbidon and Greene 2005) only reinforces increased perceptions of asylum seekers and refugees as criminals. Figure 1 conveys underlying notions of Criminality; the impression of endlessness with numerous refugee tents lined up into the distance shows both the extent of the issue of living in exile in a rather permanent structure, and emphasizes the unregulated status of individuals and families waiting to be recognized as refugees and possibly resettled (Fig. 7).



Fig. 7 Criminalization. Asylum seekers at the Manus Island detention centre (Source: Australian Broadcasting Corporation 2016)

7 Conclusion and Future Directions

One question that commonly comes up when my students discuss visual representations of asylum seekers and refugees is whether there is in fact a “right” way to portray issues linked to forced migration, detention, exile, humanitarian crises, or resettlement. How do we avoid reinforcing negative ideas or stereotypical framings and capture positive images without “sugar-coating” refugees’ realities as Gilligan and Marley (2010) caution against? How does one strike a balance between showing what happens without being voyeuristic and adding to “poverty porn”? This is arguably one of the key challenges for photographers in this context. From a research perspective, these questions will continue to guide visual analyses and are by no means easy to answer. The growing body of literature on the topic signifies a shift in the nature of the conversation on visual representations of asylum seekers and refugees.

Kurasawa’s framework offers a useful starting point to explore dominant themes in visual representations of refugees and asylum seekers. Through this process, it can be identified what key aspects can contribute to how refugees are imagined in the minds of Western audiences, and how these notions influence strong (and mostly negative) public opinion and (mostly harsh) government policy. The important dimensions of Feminization, Childhood, and Criminalization have become increasingly evident in contemporary visual depictions and as such, deserve more attention; they add rich dimensions to Kurasawa’s tropes and make the focus of visual analysis in this field more specific. A broader reflective approach to visual analysis can therefore illuminate some of the more intricate aspects of photography and images that convey the experiences of asylum seekers and refugees, by drawing on technical as well as more conceptual approaches. This way, cross-cultural research in this field can achieve the aim of challenging what Foucault (1988, p. 154) refers to as “unconsidered modes of thought,” to provide broader perspectives on the topic.

Future research in this field could focus on different sources across timeframes. In terms of sources, visual representations of asylum seekers and refugees are abundant. Common sources include: international NGO and government websites and their publications, public and private accounts on social media, photographic collections and online repositories, cartoons and photographs in the media (print and online), artwork and drawings (by asylum seekers and refugees, or by other artists), videos, posters and advertisements, or graffiti (like Banksy) to name but a few. Comparisons between sets of images across these sources using a reflective approach would add rich dimensions to this discussion by showing commonalities and differences in how similar issues are represented across sources.

In relation to timeframes, visual representations of asylum seekers and refugees clearly shift over time, and tend to change drastically around catastrophic events that receive worldwide attention, like the drowning of Aylan Kurdi or the terrorist attacks in the United States in 2001, in France in 2015 and 2016, and in Belgium and Germany in 2016. It would be enriching to compare whether contemporary representations differ from previous eras such as the coverage of the Gulf War in the 1990s (see Lenette and Miskovic 2016). Comparing when and how these shifts

occur could provide important insights on the motivations behind emphasizing one aspect of refugee-ness over another, and how major events like terrorist attacks in Western nations affect the tropes used in visual representations. Visual analysis can provide an engaging and textured way of understanding complex issues and there are many opportunities to develop this area of research in cross-cultural research.

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Autoethnography as a Phenomenological Tool: Connecting the Personal to the Cultural 105

Jayne Pitard

Contents

1	Introduction	1830
2	The Purpose of a Phenomenological Study	1831
3	Autoethnography as a Phenomenological Research Tool	1832
4	The Influence of Culture in Building Relationships	1834
5	Structured Vignette Analysis	1836
6	Explanation of Research Terms	1840
7	An Example of a Structured Vignette Analysis	1840
7.1	Vignette: Leaving the Past behind	1841
8	Conclusion and Future Directions	1842
	References	1843

Abstract

Autoethnography retrospectively and selectively writes about experiences that have their basis in, or are made possible by, being part of a culture and/or owning a specific cultural identity. Telling about the experience though must be accompanied by a critical reflection of the lived experience in order to conform to social science publishing conventions (Ellis et al., *Forum Qualitat Social Res* 12, 2001). In researching my role as the teacher of a group of vocational education professionals from Timor-Leste, I conducted a phenomenological study using autoethnography to portray the existential shifts in my cultural understanding. I used vignettes to firstly place me within the social context, and then to explore my positionality as a researcher, carefully monitoring the impact of my biases, beliefs, and personal experiences on the teacher–student relationship. Initially, I lacked structure in my vignettes, and found it difficult to maintain a format which would guide the reader through my developing cultural awareness.

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In searching for analytical and representational strategies that would enable me to increase self-reflexivity and honor my commitment to the actual, I used vignettes to describe (show) moments of cultural existential crises, and then explore my experiences by reflecting on the reactions I had, and the actions I subsequently took, in dealing with these crises (telling). My structured vignette analysis framework helped me to reveal layers of awareness that might otherwise remain experienced but concealed, and to take the reader on a collaborative journey of cultural discovery. In this chapter, I present to you my framework as used in a cross-cultural setting.

Keywords

Autoethnography · Vignettes · Phenomenology · Cultural understanding · Structured vignette analysis

1 Introduction

An autoethnographic anecdote:

As they arise from their seats the two women's eyes meet nervously. They approach the front of the classroom and commence their PowerPoint presentation. The first student addresses the slides in a quiet, hesitant voice struggling with pronunciation. The second student stands aside, silent, a look of consternation clouding her expression. At the conclusion of the slide presentation, the student announces that her colleague will lead the learning activity. She steps forward as a slide appears on the screen with what looks like words of a poem or song written in Tetun, the indigenous language of Timor-Leste. She starts singing in a melodious voice and encourages her co-students to join in. It appears that the song is well known to all the students as their voices rise in unison. The student leading the song becomes animated, smiling, clapping her hands and moving her body in rhythm. She looks happy for the first time since I met her one week ago. In an explosion of understanding, I realize this student is not speaking English. Memory flashes of other students speaking to her in whispers, and her puzzled facial expressions during my explanations of our activities, astound me. I hear myself congratulating the pair on their presentation and call for a ten minute break.

Autoethnography is a valuable tool for researchers when undertaking a study of the self, interacting with people within a culture. It is a research tool for writing from the heart about the researcher's experience of being part of or studying a cultural experience. Culture refers beyond ethnicity to include personal differences in the way one orients to the world, such as through privilege (being born into privilege or the absence of privilege), physical ability, emotional trauma, and religious, sexual, and political difference. Culture can also refer to a professional culture such as an experienced health worker interacting with someone who has no previous experience of interacting with the health industry.

My field of work and research is education, but the framework I developed to assist my methodology in my autoethnography adapts very well to the health and social sciences, and I wish to present it to you in this chapter. In researching my role as a white Australian teacher of a group of vocational education professionals from

Timor-Leste, I searched for a representation of shifts in my cultural understanding which would allow me to identify the very personal progression of my cultural emergence. I conducted a phenomenological study using autoethnography to highlight the existential shifts in myself, as I developed my relationship with my culturally different students. I used vignettes to place myself within the social context, to explore my positionality as a researcher and to carefully self-monitor the impact of my biases, beliefs, and personal experiences on the teacher–student relationship (Pitard 2016). To assist my analysis, I developed a structured method for analyzing each vignette to reveal layers of awareness that might otherwise remain experienced but concealed. This method of structured vignette analysis is well suited to research within the health and social sciences fields, where the researcher wishes to explore interactions (the lived experience) with those whose cultural background might give them a different perspective. In this chapter, I explain the purpose of a phenomenological study (the study of the lived experience), how autoethnography is useful in revealing the self in a cultural context, the influence of culture in building relationships, and how my structured vignette analysis builds a story without the need for an overarching narrative. I provide an example to highlight the usefulness of this method.

2 The Purpose of a Phenomenological Study

Phenomenology is essentially the study of lived experience or an event as experienced in the life world (Van Manen 1990). It considers the world as lived by a person, and not as an experience that is separate from a person (Lavery 2003). Phenomenology is a methodology that is helpful for us to understand the nature and meaning of everyday experience. With this methodology, we can investigate the meaning of participants' experiences of a phenomenon, in which the researcher is either an observer or a participant (Van Manen 1990). In essence, "phenomenology describes how one orients to lived experience" (Van Manen 1990, p. 4). Husserl (1970 [1936]) asserts that although all knowledge begins with experience, not every experience produces knowledge. How we interpret the lived experience determines whether developed knowledge will result. Generally, we view the experience as something that happens to us (beyond our control) and which we react to in the moment, and then we can see the experience as something we become conscious of and begin to interpret (Pitard 2016).

Take for example the death of a patient. The prereflective stage is when the experience happens to us, before we consciously start thinking about it. We suspend our judgment and set aside our assumptions, to instead analyze the phenomenon itself, in its purity. We are no longer holding the hand of a patient with a beating heart. We have experienced the passing of life. The sensation is real and yet it is not. Husserl describes it as "an *epoche* – we call it the 'transcendental reduction' ... an accomplishment of a reduction of 'the' world to the transcendental phenomenon 'world'" (p. 58). This stage is referred to variously in the literature as the *epoche*, transcendental reduction, phenomenological reduction, or bracketing (Husserl 1970

[1936]; Lavery 2003; Friesen et al. 2012; Van Manen 2014). We place ourselves at the moment of impact and describe our sensations before our mind has time to process and analyze these sensations (Pitard 2016). According to Husserl, the *epoche* dictates that any phenomenological description must be written in the first person to ensure it is described as it is experienced. The writing of this *epoche* is very personal to us, to the physiological sensations this death produces in us, and the feelings it invokes in us. We might then become aware of our surroundings, of family who must be consoled, and of procedures which must be followed.

3 Autoethnography as a Phenomenological Research Tool

Autoethnography is a contentious qualitative research methodology which speaks from the heart about existential crises or transformational experiences (Anderson 2006; Denzin 2006; Ellis et al. 2011). It allows researchers to focus on “ways of producing meaningful, accessible and evocative research grounded in personal experience” (Ellis et al. 2011, p. 2) by encouraging the researcher to write from the heart. Autoethnography is self-focused and context-conscious (Reed-Danahay 1997; Ngunjiri et al. 2010). It is a constructive method for researching the health practitioner–patient relationship where the practitioner and patient or patients’ relatives are from diverse cultures and economic backgrounds, as it allows an in-depth exploration of the researcher as a health practitioner interacting within cultural difference. Writing about the experience of a phenomenon within an autoethnography can be a very powerful research methodology (see also ► Chap. 30, “Autoethnography”).

The use of autoethnography within a phenomenological study produces real-world knowledge as experienced by the person at the center of the experience. However, in merely relating the experience as a story, it is possible the insight gained from the experience may elude the reader. As I have written previously (Pitard 2016), within a phenomenological framework, the use of autoethnography as a research tool places the self at the center of a cultural interaction, as it explores the impact of an experience on the writer. Autoethnography is an approach to research and writing to “describe and systematically analyse (*graphy*) personal experience (*auto*) to understand cultural experience (*ethno*)” (Ellis et al. 2011, p. 1). Autoethnography retrospectively and selectively indicates experiences based on, or made possible by, being part of a culture or owning a specific cultural identity. It draws the reader into a very personal experience which encourages empathy between the reader and the author, and promotes a deeper cultural understanding (Ellis and Bochner 2000). However, in order to conform to social science publishing conventions, the experience must be accompanied by a critical reflection, an analysis, of the lived experience which invites the reader to carefully consider the cultural experience being described. Autoethnographers must “use personal experience to illustrate facets of cultural experience” (Ellis et al. 2011, p. 9). The use of vignettes to examine and analyze lived experiences can provide a window through which the reader can gain an understanding of the insight which comes from

placing a person with one cultural identity in a setting of different cultural norms (Pitard 2016).

Chang (2007) warns against self-indulgent introspection in autoethnography which tends to distance the reader from the cultural interaction taking place. She argues that “autoethnography should be ethnographical in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation” (p. 207). Autoethnography should emphasize “cultural analysis and interpretations of the researcher’s behaviours, thoughts, and experiences in relation to others in society” (p. 207). I contend that autoethnography should also draw the reader into “the inner workings of the social context studied, thereby enhancing the reader’s understanding and knowledge of the culture studied. This could be explained as a collaborative journey between the reader and ...the author” (Pitard 2016, p. 5).

Reed-Danahay (1997) proposes that autoethnography connects the social to the cultural by exploring the self within the cultural context, to extend knowledge and understanding of the sociological setting within a culture. Chang (2007) “emphasizes the cultural (ethnographic) nature of autoethnography stating that this characteristic of autoethnography distinguishes it from other forms of narrative writing by connecting the personal to the cultural, the self to the social, where the self refers to the ethnographer self” (Pitard 2016, p. 6). Alexander (2005, p. 423) states that autoethnography “engages ethnographical analysis of personally lived experience.” We can argue then that the prolific and significant writers on autoethnography agree that the cultural interaction which takes place is equally as important as the experience itself. Remember what was stated earlier in this chapter – culture does not rely on ethnicity. It refers to different ways of being.

Difference can produce misunderstanding which can prevent us from fully comprehending the essence of our experience with another culture. Ellis and Bochner (2000) suggest that the development of autoethnography has been driven by a desire to produce significant, accessible, and evocative accounts of personal experience to intensify our ability to empathize with people who are different from us. These accounts may provide health practitioners with an opportunity to develop a depth of understanding they may not already have developed through their own experience or through contact with different “others.” In other words, this empathy can be learned through the telling and critical reflection as experienced by others. Therein lies the collaborative journey between reader and author.

As well as the benefit to readers, autoethnography permits the researcher a wider research lens with which to study their lived experience because it acknowledges the researcher’s influence. Autoethnography accommodates and even embraces subjectivity. The process of autoethnography involves writing about and analyzing selected epiphanies that stem from interactions involving being part of a culture (Ellis et al. 2011). Even within the selection of which epiphanies to consider, the researcher acknowledges their influence on the research. Aligned with researcher influence though, Ellis et al. propose that it is a duty of autoethnographers in analyzing their personal experience to consider ways others may experience similar epiphanies. They further contend that it is in the analyzing of personal experience in such

epiphanies that the characteristics of a culture become familiar to those inside and outside the culture. In the autobiographical style of writing used in autoethnography, it is important to show through personal descriptive writing how the epiphany was invoked through thoughts, emotions, and actions. Emphasizing ethnographic performance, Alexander (2005, p. 423) states that showing is “less about reflecting on the self ... as an act of critically reflecting culture, an act of seeing the self through and as the other.” This showing can make writing emotionally rich; but to enable the reader to consider the events in a more abstract way, it needs to be balanced with some telling (Pitard 2016). Telling is a style used by an author to state what happened from a less emotional, involved standpoint (Ellis et al. 2011).

I contend that the challenges of Chang (to focus on the cultural interaction to distinguish it from other forms of narrative; 2007), Ellis et al. (to consider the ways others may have experienced our epiphanies; 2011), and Alexander (to balance our writing with showing and telling; 2005) urge writers to search for analytical and representational strategies to enable increased self-reflexivity (Pitard 2016). This honors the commitment to the actual while providing the reader with an opportunity to think about the events in a more abstract way. To conform to this version of autoethnography, I used anecdotes to describe (show) moments of cultural existential crises and explored my experiences, by reflecting on my reactions and subsequent actions, in dealing with these crises (telling) (Pitard 2016). Adopting this method of self-conscious reflexivity (Ellis and Bochner 1996) specifies the researcher’s exact relation to self and to culturally different others (Alexander 2005). In striving for this process of showing and telling through the use of narrative vignettes and memory recall based on notes recorded as the event happened, an analysis of the researcher’s reflexivity to these crises will reveal how the researcher responds at a more academic level. This reflexivity is a demonstration of how the professional reacts to these very personal lived experiences, which helps to emphasize the cultural impact in the analyses of the narrative vignettes. They are not a simple story of the researcher’s life. They are a story of the researcher’s interaction with another culture. Understanding our interactions with another culture first requires us to understand what culture is, and how it impacts our relationships.

4 The Influence of Culture in Building Relationships

Among researchers and authors, there appears to be a common premise that culture is a learned set of shared interpretations about “beliefs, norms and social practices” (Lustig and Koester 2006, p. 142), of a “historically shared system of symbolic resources through which we make our world meaningful” (Hall 1959, p. 4), a “collective programming of the mind” (Hofstede 2011, p. 3) that differentiates groups of people. Culture then, rather than stemming from genetic factors, is derived from the social environment. It is learned, not inherited (Spencer-Oatley 2008). Hofstede (1991, p. 8) contends that although certain aspects of culture are physically visible, their meaning is invisible; their cultural meaning “lies precisely and only in the way these practices are interpreted by the insiders.” Insiders refer to those of a

similar cultural background. Hofstede's model of the three levels of uniqueness in human mental programming – human nature, culture, and personality (Hofstede 1994, p. 6) – places human nature as common to all humans. It represents our ability to feel fear, anger, love, joy, sadness; the need to associate with others; to play and exercise; plus the ability to observe the environment and talk about it with others (Spencer-Oatey 2008). How we communicate these feelings is dictated by our culture, and the dichotomy exists that what is perfectly acceptable to one culture can be absolutely repugnant to another. Spencer-Oatey (2008) contends that culture is as much an individual, psychological construct as it is a social construct. Personality is individual as it represents a person's characteristics which are partly inherited and partly dictated by culture. Social and cognitive processing may vary in individuals from the same culture, in accordance with their life experience, and forming conclusions about a culture based on stereotypes should be avoided. Lastly, culture has both universal (etic) and distinctive (emic) elements. An example of an etic element is that common to all cultures, people feel closer to their family and relatives and those they view more similar to themselves than they do to those they view as different. However, this may be adapted in diverse cultures to include broader or smaller groups, thus making it emic. It is the emic elements of a culture which are of greatest interest to researchers. Avruch (2004, p. 20) states culture is "rooted deeply in on-going or past social practice and is to some extent situational, flexible and responsive to the exigencies of the worlds that individuals confront" (see also ► Chap. 88, "Culturally Safe Research with Vulnerable Populations (Māori)").

In dealing with unknown cultures, the inability to predict outcomes of intercultural communication often results in anxiety, stemming from a lack of understanding of the implied rules by which the interaction will occur (Gudykunst and Nishida 2001). Gudykunst (2005) regards uncertainty in intercultural communication as a "cognitive phenomenon"; an inability to predict attitudes, feelings, and behavior outcomes as a result of not being able to read both verbal and nonverbal cues. In explaining his theory of uncertainty and anxiety in intercultural communication, Gudykunst (1988) emphasizes the necessity of recognizing that at least one of the participants is a stranger. He argues that although the stranger is situated within the group at the time of the intercultural communication, he/she is outside the group in terms of cultural alignment. When a health practitioner is communicating with the relatives of a patient from a different culture, she is the stranger within the group. However, once she steps outside that group into the wider health network, the patient's relatives can become the strangers (displaced) within the Australian healthcare system. In this situation, Gudykunst's theory assumes the strangers' initial experiences with a different group are experienced as a series of crises where the stranger is not cognitively sure how to behave. The stranger is basing their reactions to the group on known or previously experienced interactions within their own culture, often referred to as implicit theory or habitual reactions. This can be disorientating and disconcerting as the stranger realizes the known ground rules or reactions of habit do not apply with those from another culture, creating heightened awareness of situation-behavior sequences (Gudykunst 2005). Matsumoto et al. (2005) assert self-concepts and individual values affect communication styles across

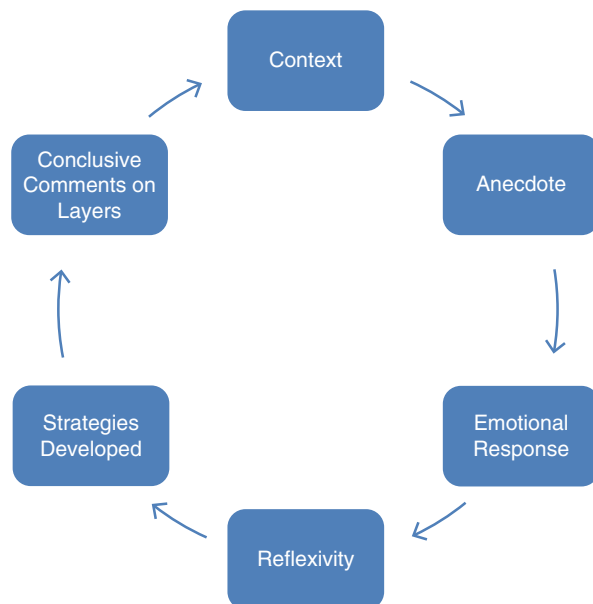
cultures and that differences exist in the use of apologies, self-disclosure, compliments, and interpersonal criticism. The pervasive impact of culture on all aspects of the communication process underpins the difficulty people from diverse cultures will have in anticipating the meaning of verbal communication based on nonverbal cues. A critical examination of intercultural experiences will reveal the process of building relationships between cultures. Autoethnography is a tool for critical examination of intercultural experiences, and vignettes, describing a sequence of such experiences, can build a profile of intercultural communication which can expose a growth in cultural adaptation. In the next section, I will describe my structured vignette analysis.

5 Structured Vignette Analysis

My practice of structured vignette analysis within my autoethnography allowed me to examine my own contribution to the development of my relationship with my culturally different students. I use anecdotes within my vignettes to describe my experience *as it happened*. Van Manen (2014) uses the term *anecdote* to describe writing about the reduction moment or *epoche*. He states that “what makes anecdotes so effective is that they seem to tell something noteworthy or important about life” (p. 250). He describes the use of the anecdote in autoethnographic writing to give voice to the unconscious, deep, and pathic sensations experienced in the reduction moment. He contends that phenomenological writing should try to find “expressive means to penetrate and stir up the pre-reflective substrates of experience as we live them ... to discover what lies at the ontological core of our being” (p. 240). We should use the manifestation of our anecdotes, the words we use to express our prereflective experience, to awaken memories of the event that remained previously concealed. In this regard, researchers should allow themselves the liberty of writing freely while expressing the lived experience within their anecdotes, and only allow themselves reflection and editing when writing analyzes of the moments described in their vignettes (Pitard 2016). This almost hypnotic, trance-like state of expressing the existential moments captured in anecdotes allows the unconscious to divulge the depth of experience. Humphreys (2005) uses embedded autoethnographic vignettes with the intention of creating stories to stimulate an emotional response and provoke understanding from his readers. He connects with his innermost feelings during periods of career stress and describes experiences that his audience can connect with also. The reader is transported to the moment of truth for Humphreys.

In an effort to make sense of the cultural impact of outstanding (impactful, transformational) interactions with the culturally different, when writing vignettes the researcher should mentally transport themselves to the prereflective moment using journal entries and photographs as prompts. While it is acknowledged the retelling of these stories has already altered the prereflective experience simply through putting the experience into words (Van Manen 2014), anecdotes (the recall of the *epoche* within a vignette) are the closest a researcher will be able to transport

Fig. 1 Structured vignette analysis (Pitard 2016)



themselves to the prereflective moment of happening. These vignettes should record how the researcher makes sense of what happened, as a practitioner. It is essential to use reflexivity as a means to achieve an expansion of understanding in cultural interactions.

The use of a structured vignette analysis permits individual vignettes to describe distinct experiences while connecting these stories through recounting the context and revealing new strategies developed to cater for the researcher's growing cultural awareness (Pitard 2016). This is achieved through the development of a six-step framework (see Fig. 1). The framework also has the advantage of revealing several layers of awareness, described by Ronai (1995) as the layered account. The different voices of the researcher add to the richness of the analysis as the personal leads into the academic reflexive voice. Each of these layers adds a different perspective to a vignette. The six steps in my structured vignette analysis are listed in Fig. 1 and explained individually in the following section.

Context

Reality is known through socially constructed meaning (Guba and Lincoln 1994; Ritchie and Lewis 2003; Trede and Higgs 2009). Truth is negotiated through dialogue and the context of that dialogue is vital to the shaping of the data. It is through the dialectical process (the tolerance for holding apparently contradictory beliefs (Peng and Nisbett 1999) that members of a community with different cultural backgrounds come to an understanding of their social world. The researcher and the participants are "changed" by the experience and the new knowledge is a result of

this interaction, bound by the timing of the interaction and the context in which the interaction took place. According to Dervin (2003, p. 130), “context is something you swim in like a fish. You are in it. It is you.” Dervin proposes that most writers about context postulate its meaning as a focus on process. She states it is “attention to process, to change over time, to emergent and fluid patterns” (p. 116). Context becomes known when the researcher turns the research lens back on the researcher. Interpretivism and constructivism manifest understanding of the meanings behind the actions of individuals to understand “the entire context, at both the macro and micro environmental level” (Pickard 2007, p. 13). Within the context relevant to each individual vignette, the reader discovers the progress of the researcher and the “other” over time (Pitard 2016).

Anecdote

In narrative anecdotes, the prereflective impact is recalled to return the researcher to the conditions before reflection or the written word impacts on the recall, to restore contact with the lived experience (Van Manen 2014). Van Manen prescribes “a certain succinctness” in the style of the anecdote (p. 252). He suggests “a set of guidelines for gathering powerful narrative material or for editing appropriate lived experience descriptions into exemplary anecdotes.” These guidelines are presented below:

1. “An anecdote is a very short and simple story.
2. An anecdote usually describes a single incident.
3. An anecdote begins close to the central moment of the experience.
4. An anecdote includes important concrete details.
5. An anecdote often contains several quotes (what was said, done and so on).
6. An anecdote closes quickly after the climax or when the incident has passed.
7. An anecdote often has an effective or ‘punchy’ last line: it creates punctum” (p. 252).

Emotional Response

This relates to the immediate physiological and emotional responses experienced as the existential crisis unfolds. An emotional response is involuntary and unconscious. Hockenbury and Hockenbury (2011) describe three components to an emotional response: a subjective experience, a physiological response and a behavioral response.

Reflexivity

Berger’s definition of reflexivity takes into account the positionality of the researcher:

Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of a researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome. (Berger 2013, p. 220)

The emphasis on reflexivity as a process, rather than an attitude or a single action, aligns with the philosophy that reality is constantly in flux, and the moment we observe reality, it is already changing. The automatic internal dialogue commences as soon as we experience something, and being aware of that internal dialogue and taking control of it is the essence of reflexivity. To take control of this internal dialogue, Berger argues that:

researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and the universal (p. 220).

Counter transference is a term used in psychodynamic language (Berger 2013) to explain the impact of clinical practitioners' own history and issues on their understanding of and reactions to the client. According to Hughes and Kerr (2000), Freud believed the practitioner's formative dynamics (assumptions based on personal life experience and important, impactful early relationships with adults such as parents) could transfer to the patient, and vice versa. He coined the term counter transference to describe this process.

Transference involves the projection of assumptions based on a previous experience to a present experience (Hughes and Kerr 2000). Reflexivity in research is the researchers' acknowledgment of and response to the impact of their own history and life issues on their interactions with their research participants. Reflexivity acknowledges that counter transference occurs in research involving participants, from the participants to the researcher, and from the researcher to the participants.

Reflexivity has been increasingly recognized as an essential strategy in the process of producing knowledge through qualitative research. Watt (2007, p. 82) explains that "since the researcher is the primary 'instrument' of data collection and analysis, reflexivity is deemed essential." According to Russell and Kelly (2002), reflection allows researchers to become aware of not only what enhances their ability to see, but also what may inhibit their seeing. Questioning one's assumptions can expose taken-for-granted attitudes that might not apply to the cultural group with whom you are interacting (Pitard 2016).

Strategies Developed

The use of reflexivity to expand understanding of an interaction between oneself and the other offers an opportunity to develop strategies to transform future interactions into more positive experiences. Exposing the strategies developed, as a result of the experience, to deal differently with similar experiences in the future can help the researcher and the reader to understand the lessons learned.

Conclusive Comments on Layers

Bringing together the different layers of account provides a concise summary of the effects of the experience and how it developed the researcher's understanding of a different culture.

6 Explanation of Research Terms

In this chapter, I have referred to the terms *epoche*, *phenomenological reduction*, and *bracketing*, used variously to describe the transcendental reduction (Husserl 1970 [1936]) of the lived experience. While I reference these terms to assist in explaining the transcendental reduction or prereflective stage of studying the lived experience, I do not provide a serious analysis and critique of these concepts. These terms are offered by way of assisting you to understand the phenomenological nature of autoethnography and are not intended to provide an in-depth analysis of the terms themselves (Pitard 2016).

In my structured vignette analysis, I use the term vignette in reference to my framework of six-stage analysis. My anecdote sits within the six stages of the vignette. The use of the terms *anecdote* and *vignette* are often interchanged in qualitative research methodology and my search for an explanation of their interchangeability resulted in my preference to use the term vignette to describe my six-step structured framework. I use the term anecdote to distinguish the narrative of my lived experience, which is Step 2 in my framework and I have written my anecdote, my lived experience, in the present tense. It is presented in italics to distinguish it within my vignette, as the anecdote is central to the vignette. The Sage Encyclopedia of Qualitative Research Methods does not contain an entry for anecdote and describes vignettes as “stimuli that selectively portray elements of reality to which research participants are invited to respond” (Hughes 2008, p. 918). No entry describes vignettes as autobiographical stories written within an autoethnography. Although Ellis et al. (2011), Humphreys (2005), and Ronai (1995) all use the term vignette to describe the writing of their personal experiences within autoethnography, they do not identify the structure of their vignettes into steps which include the writing of an anecdote within their vignettes. It is noted that earlier writers on phenomenological research use the term anecdote to describe the telling of their lived experience and Van Manen (2014) provides a set of guidelines for writing powerful narrative material in an anecdote (Pitard 2016).

7 An Example of a Structured Vignette Analysis

This example of my structured vignette analysis was developed during my PhD research and is based on my teaching practice with a group of students from Timor-Leste who came to Melbourne, Australia, to undertake study. Timor-Leste is a least developed country with a history of invasion, massacre, and destruction. I visited Timor initially to meet with strategic personnel to discuss the outcomes anticipated for these students for their study in Australia. Over the course of my research, I kept journal entries of my personal experience in understanding a different culture, developing intercultural relationships, notes on teaching strategies commenting on what worked and what did not, notes on conversations I had with students, photographs of students’ mind maps (which became their favorite method of learning),

and photographs of notes from the whiteboard in the classroom. These methods of recording my interactions with the students provided rich data to inform my vignettes. To capture as closely as possible the prereflective experience in my vignettes, I used my journal entries as a springboard to create a trance-like state in which I propelled myself back in time to the actual experience, the point of contact (Pitard 2016). I allowed the vision to flow, capturing the essence of body language, facial expressions, and physical sensations, such as a racing heart and altered spatial awareness. I offer a sample vignette below which is situated in my first visit to Timor, where I was accompanied by colleagues from my university in Melbourne, Australia, who had significant experience there.

7.1 Vignette: Leaving the Past behind

7.1.1 Context

My colleagues and I attended an alumni dinner, organized and hosted by my Australian university. At this point in our journey, I was finding it difficult to be present at the dinner because of ongoing chronic fatigue. Over a period of 18 years, I had learned to manage this condition through withdrawal for rest at strategic intervals, and I sensed this might be one of those occasions; however, I was strongly encouraged to attend the dinner, and I did so reluctantly.

We took a taxi to a Chinese restaurant in a part of Dili I had not visited. The restaurant was on the ground floor of a building in a street lined with two-story buildings of basic construction. The restaurant was decorated as part Chinese and part Timorese, so it gave the feeling of being both familiar and fragile. Two university colleagues, with whom I had worked in Melbourne, were in Dili with a group of Bachelor of Education students from Melbourne undertaking their school internships in Dili. These two colleagues also attended the dinner. It was hot and for the first hour everyone stood around chatting and drinking.

7.1.2 Anecdote

I am finding being on my feet very difficult. Fatigue is gripping my chest and my legs feel weak. I scan the room for a kind looking face and engage a Timorese alumna in conversation about her study and what this means to her in light of the declaration of independence in Timor in 2002. As she smiles broadly throughout our conversation, I feel the need to know how she can be happy when her country has been so devastated by invading forces. I ask if she lost family members during the invasion and massacre. Her smile disappears. I feel the blood rushing to my face as I recognise my intrusion into her private world. She describes those members of her family whose lives have been sacrificed. Almost too quickly, I express admiration for her positive attitude and, as her smile returns, she explains there is no point in looking back, that she and her people must build a new, strong nation and to do this, they need the assistance of the Indonesians. Confusion overwhelms me as I recognize my own anger towards the invaders. Gripped by fatigue, tears well in my eyes. I do not understand. I move swiftly towards the exit for a breath of fresh air.

7.1.3 Emotional Response

At first glance, this entry in my notes may not seem to be the intense sort of experience which might provoke an epiphany in general, but it had a very striking impact on me, which remains with me still. I felt confused by the forgiveness inherent in the Timorese attitude to the loss of family, culture, and wealth. Based on my cultural experience, I anticipated anger would be an undercurrent; but it was not. I was humbled by the happiness and excitement I was feeling all around me that night, and I had anticipated that it stemmed from the release from invasion and violence. However, the violence and loss they had experienced was in the past and, although they mourned for lost loved ones, they seemed not to place any blame as they looked to the future. Stunned by this, and fatigued beyond endurance, I was overwhelmed by guilt for my own feelings of anger.

7.1.4 Reflexivity

It was not until a few months later when I was reading in *The Age* online newspaper an article (Green 2013) based on an interview with Ms. Rosa Storelli, the displaced principal of Methodist Ladies College in Kew, Victoria, that I understood this attitude at a deeper level. The author stated his admiration that Ms. Storelli held no ill feeling to those who had moved against her to displace her from her position as a successful and much loved principal of a girls' school. When asked how she could manage this, Ms. Storelli remarked that if she harbored ill feeling, it would affect her ability to move forward in her life. She stated that she was not going to allow anybody else to dictate her future, so she had to shed any feeling she had about people who had influenced her past. I was deeply moved by this statement. In thinking about this, I recalled my conversation with the university alumna in the restaurant in Dili and experienced an epiphany of understanding so profound I realized that the Timorese were conceivably more deeply spiritual and wiser than me. In terms of coping with cultural adversity, this was very humbling.

7.1.5 Strategies Developed and Concluding Comments on Layers

I learned from this experience that if I was to serve my students' forward development, I had to adopt their attitude. What had happened in the past must stay in the past. Our task would be to work together toward the future development of the TVET system in TL. My position as the facilitator of their learning compelled me to address current and future issues. The past was theirs to deal with.

8 Conclusion and Future Directions

Autoethnography connects the personal to the cultural. It provides a qualitative research method which allows us to explore the emotions, concerns, misunderstandings, blunders, and frustration which can emerge in developing relationships with people within a cultural setting. Parks (1997) argues for a scholarly representation of the autoethnographic research experience, stating that to be evocative is insufficient to make a work scholarly. He calls for deeper levels of reflection and analysis, where

the researcher develops the relationship between the personal experience and broader theoretical concepts. Others such as Garrett and Hodkinson (1999), Bochner (2000), Richardson (2000), Sparkes (2000), Holt (2003), Duncan (2004), and Wall (2006) discuss the role of criteria in judging the validity of autoethnography, and conclude that traditional criteria do not apply to autoethnography. There is an acknowledgment that different epistemological and ontological assumptions inform autoethnography simply because it involves an individual account. It is interpretivist, postmodernist, and does not rely on neutrality and objectivity. It is not disembodied, but rather relies on the tenet that we cannot separate ourselves from how we experience our lives. Richardson (2000, p. 11) argues that beyond criteria for judging validity, narratives (including autoethnography) should “seek to meet literary criteria of coherence, verisimilitude, and interest.” A scholarly presentation of autoethnography can be achieved through my structured vignette analysis. This framework of analysis exposes my sense-making of teaching students from Timor-Leste for the first time. It is my unique story which captures my shock and my reflexivity. My structured vignette analysis provided me with the framework to structure my responses in an organized (coherent), predictable method (verisimilitude/reliability) to guide the reader through my experience with my culturally different students. I wrote 15 vignettes, without an overarching narrative, which take readers on a collaborative journey (interest) into my growing cultural awareness, and how I adapted my teaching to cater for the difference I perceived (connecting theoretical concepts). To balance my research (for the students’ voices to be heard), I also conducted a case study of their experience. The result is a story of developing relationships amidst an emerging understanding of the cultural differences and human sameness of people of diverse backgrounds, flung together to achieve a common objective. Developing your own understanding of your experience of cultural difference could enhance your professional practice. Using autoethnography to write from the heart in cross-cultural experiences can be painful, shocking, and revealing. Moving beyond these revelations to the analytical and reflexive phases has the positive impact of adding to the body of knowledge in cross-cultural, professional interactions. This, in turn, develops the possibility that those whose experience in such matters has not afforded them the learning which can be gained from the moment of impact, may read your structured vignette analysis and experience the moment of truth for themselves. Be courageous in your research. Seek to inspire.

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Ethics and Research with Indigenous Peoples

106

Noreen D. Willows

Contents

1	Introduction	1848
2	Indigenous Peoples and Right to Self-Determination in Health Research	1850
3	Barriers to Addressing Health Inequities and Health Disparities Experienced by Indigenous Peoples	1851
4	The Right of Indigenous Peoples to Participate in Decolonizing Research that Improves Health and Well-Being	1852
5	Research Frameworks for Research with Indigenous Peoples: Examples from Canada	1854
6	Institutional Research Guidelines: Canada and New Zealand	1856
6.1	Canada: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans: TCPS 2	1858
6.2	Ethical Guidelines for Health Research with Māori in New Zealand	1859
7	Guidelines for Health Research Developed by Indigenous Communities or Agencies	1860
8	Building Capacity to Do Ethical Research with Indigenous Peoples	1861
8.1	Institute on the Ethics of Research with Indigenous Peoples	1862
8.2	Centre for Excellence in Indigenous Health	1863
8.3	Community-Based Research and Evaluation Certificate Program	1863
8.4	Master of Public Health: Native Hawaiian and Indigenous Health Specialization	1864
8.5	Community Mobilization for Healthy Lifestyles and Diabetes Prevention Training Program	1864
8.6	Summer Research Training Institute for American Indian and Alaska Native Health Professionals	1865
9	Conclusion and Future Directions	1865
	References	1867

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1847

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Abstract

Many Indigenous peoples have poorer health compared with the settler populations that colonized their territories. States and academic institutions have an obligation to support ethical research with Indigenous peoples that results in the elimination of health disparities. Decolonizing research is required that serves to restore health in conformity with enduring Indigenous values that affirm life. Indigenous peoples may have concerns that health research under the control of outsiders will come to conclusions about Indigenous health disparities that stereotype, pathologize, and/or marginalize Indigenous peoples; be instrumental in rationalizing colonialist perceptions of Indigenous incapacity and the need for paternalistic control of Indigenous interests, or deduce that Indigenous peoples are sick and incapable of self-care. Health research that respects Indigenous self-determination, and is safe, ethical, and useful for participants, requires increased capacity among Indigenous and non-Indigenous peoples alike. Indigenous peoples have the right to control research that generates knowledge affecting their well-being. Community members need workshops and training sessions that will inform them how to negotiate with health researchers, let them know their rights as research participants, and build their skills to conduct their own research. Non-Indigenous researchers require appropriate ethical guidelines to follow and training opportunities that offer guidance on Indigenous ways of knowing, the social determinants of health, strength-based research approaches, community-based participatory research, and how to engage in culturally appropriate ways with Indigenous peoples. Researchers wanting to pursue a specialization in Indigenous health research need support from academic leadership and funding agencies to be successful in their endeavor.

Keywords

Community-based participatory research · Decolonizing research · Health disparities · Health inequities · Indigenous peoples · Research ethics

1 Introduction

The United Nations Declaration on the Rights of Indigenous Peoples was adopted by the General Assembly in 2007 (United Nations 2008). Article 24 of the Declaration indicates that States will take the necessary steps to ensure that Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. Given this proclamation, this chapter argues that States can help to ensure that a high standard of health is achieved by Indigenous peoples by supporting ethically conducted, innovative research programs based on scientific excellence and Indigenous community collaboration. State-supported research of this nature is occurring in some countries. For instance, the Institute of Aboriginal Peoples' Health (IAPH) is one institute of the Canadian Institutes of Health Research (CIHR), Canada's federal funding agency for health research. IAPH supports health

research that is conducted using the highest ethical and moral standards and that respects Aboriginal cultures, while generating new knowledge to improve the health and well-being of Aboriginal peoples (Canadian Institutes of Health Research 2011).

This chapter discusses how States, academic institutions, and Indigenous groups can support ethical research with Indigenous peoples, communities, and nations. It builds on an editorial that I wrote about the requirement for ethical principles of health research involving Indigenous peoples in Canada (Willows 2013). The editorial followed revelations by a historian in 2013 that a series of egregious nutrition studies had been conducted in Canada in the 1940s and 1950s by federal government scientists, bureaucrats, and university researchers that used malnourished First Nations children and adults as experimental material and their communities as laboratories for scientific experimentation (Mosby 2013). In the studies, researchers had exclusive control over the research process and the use of results, and they did not return meaningful results to the communities. There was no evidence that these studies resolved the malnutrition, hunger, or suffering of the children or community members included in them; rather, the beneficiaries were those who lead the research, as carrying out these studies furthered their own professional and political interests (Mosby 2013). While it is unlikely today that health research that violates the inalienable rights of research participants such as the provision of informed consent would be sanctioned within Canada, it is possible that Indigenous peoples' unique rights might be violated, or that unique considerations for conducting research with Indigenous peoples would not be followed. For example, researchers may not discern that their research creates an imbalance of power between them and Indigenous research participants; that it devalues traditional Indigenous knowledge in favor of Western scientific knowledge; that it violates community norms; or, that the findings misrepresent or stigmatize community members (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada 2014, p. 109).

In this chapter, I discuss why scientifically rigorous health research that takes into account Indigenous rights is urgently needed as well as some of the considerations for conducting ethical research with Indigenous peoples. I will refer mostly to the Canadian literature on these topics due to my familiarity with the material. Although the chapter has broad applicability to research with Indigenous populations in many countries, it will likely have the greatest application to Indigenous groups in Australia, Canada, New Zealand, and the United States for several reasons. The Indigenous peoples in Canada have geographical and/or cultural contiguity with many of the Indigenous peoples in the United States. All four countries are Western, liberal democracies, originally settled by colonizers who were predominantly of European-ancestry. Indigenous peoples in these countries are united by similarities in their colonial treatment by settler populations whereby colonization resulted in settlers usurping the land and resources of the local Indigenous peoples and appropriating and/or suppressing Indigenous peoples' lives and identities. Indigenous peoples in all four countries have poorer socioeconomic and health outcomes in comparison

to the settler majority (see also ► [Chaps. 87, “Kaupapa Māori Health Research,” ► 88, “Culturally Safe Research with Vulnerable Populations \(Māori\)”](#)).

Given the geopolitical focus of this chapter, the term Indigenous used herein has the greatest applicability to Métis, First Nations, and Inuit peoples in Canada (collectively called Aboriginal peoples in Section 35 of Canada’s Constitution Act of 1982); Aboriginal peoples and Torres Strait Islanders in Australia; Māori in New Zealand; and, American Indians, Alaska Natives (i.e., Inuit, Yupik, and Aleut peoples), and Native Hawaiians in the United States. It is important to bear in mind that settler governments conjured these terms for Indigenous peoples for political and jurisdictional purposes. Indigenous populations have much greater cultural diversity than ascribed by these labels, and may choose to use their own group’s cultural name when referring to themselves, as a decolonizing action, as a means to achieve self-determination, and for increased accuracy of identity (Allan and Smylie 2015).

The perspective of ethical research that I present partially reflects my professional experiences as a non-Indigenous health researcher working in an academic environment. My career has focused predominantly on nutrition research with First Nations communities in Canada, including the development, implementation, and evaluation of nutrition interventions (e.g., Pigford and Willows 2010; Triador et al. 2015). I aim to adopt a community-based participatory research (CBPR) approach to the work that I do, whereby I partner with First Nations community members to find culturally appropriate solutions to their nutrition concerns or nutrition-related health conditions. The viewpoints that I express in this chapter stems from my interest in articulating the practice and outcomes of CPBR with First Nations peoples (Pigford et al. 2013; Willows et al. 2016; Gokiart et al. [under review](#)); what constitutes ethical research with Indigenous peoples (Willows 2013); how to copartner with First Nations peoples (Genuis et al. 2014, 2015; Willows et al. 2016); and developing culturally appropriate frameworks to conceptualize Indigenous peoples’ health issues (Willows et al. 2012).

2 Indigenous Peoples and Right to Self-Determination in Health Research

There is no singularly authoritative definition of Indigenous peoples under international law and policy although criteria to help identify Indigenous peoples have been established by the United Nations (United Nations 2013; United Nations, [n.d.](#)). These criteria include peoples who have historical continuity with precolonial and/or presettler societies that developed on their territories; consider themselves to have distinct social, economic, or political systems, language, culture, and beliefs distinct from other sectors of the societies now prevailing on their territories, or parts of them; have strong linkages to territories and surrounding natural resources; and form at present nondominant groups of society that resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples, in accordance with their own cultural patterns, social institutions, and legal systems. Based on these

criteria, in 2016 there were more than 390 million Indigenous peoples worldwide (Food and Agriculture Organization of the United Nations 2016).

The label of “indigeneity” serves a pragmatic purpose, as it allows a diversity of groups, societies, and nations to resist domination by settler populations and to demand their entitlement to their rights as Indigenous peoples. Indigenous rights is about “unfolding *in practice* such notions as equality, procedural justice and a universal right of self-determination that the idea of human rights has always promised” (Guenther et al. 2006, p. 28, italicized in original). The application of the right to self-determination for Indigenous groups, societies, and nations requires recognition of collective rights, self-governance, and autonomy and control of lands and resources (Guenther et al. 2006). Fundamental to the exercise of self-determination, Indigenous peoples have the right to control research that generates knowledge affecting their cultural heritage (including their traditional knowledge, traditional cultural expressions, and intellectual property), identity and well-being, and to construct knowledge in accordance with self-determined definitions of what is real and what is valuable (Castellano 2004; Australian Institute of Aboriginal and Torres Strait Islander Studies 2012; see also “Indigenist and Decolonizing Research Methodology”).

3 Barriers to Addressing Health Inequities and Health Disparities Experienced by Indigenous Peoples

Improved health and well-being for Indigenous peoples through research is desired by Indigenous and non-Indigenous peoples alike. However, there are many barriers that prevent the undertaking of high-quality, ethical health research. Many Indigenous communities do not have the financial or internal human resources to address the health disparities that they face. For example, due to policies and practices that emerged from colonial ideologies, Indigenous peoples in Canada have low high school completion rates and often do not achieve a postsecondary education (Allan and Smylie 2015). Consequently, Canadian universities report an underrepresentation of Indigenous scholars in their professoriate (Ramos 2012) meaning that there are few academically trained health researchers who are Indigenous. Non-Indigenous health researchers may be reluctant to engage in research with Indigenous peoples, based on perceived barriers to conducting research with Indigenous peoples, some which have been articulated elsewhere (Castleden et al. 2015).

Fears that have been expressed to me by non-Indigenous colleagues about engaging in health research in Indigenous communities are that the requirements for undertaking ethical and collaborative research with Indigenous communities will prevent research from being scientifically rigorous, will lengthen the time to do research, and will limit the number of publications produced from the research. These concerns are generally unfounded *as long as academics are supported by their institutions and funding agencies to undertake ethical and collaborative research*. While research with Indigenous peoples can require an extensive commitment of time, academic scholars have established credible scientific careers based on

research partnerships with Indigenous communities. I have been fortunate to receive salary awards from my Provincial Government through Alberta Innovates Health Solutions, and before that, the Alberta Heritage Foundation for Medical Research that reduced my teaching and administrative load at the University of Alberta, giving me the time to fully engage with First Nations partners. Thus, it is my contention that many of the barriers that academic researchers perceive limit the production of high-quality research that addresses Indigenous health issues could be overcome if academic scholars were better supported by academic departments and faculties to engage with Indigenous communities in a respectful way.

Indigenous peoples have the right to know about their health status; the causes, nature, and treatment of their ill-health; and the resources available to improve their health (UN Office of the High Commissioner for Human Rights 2008). The task of undertaking health research in Indigenous communities to address these topics often falls to non-Indigenous peoples, many who have been trained exclusively in Western ways of knowing and conducting science, and who may have little knowledge of Indigenous peoples. Indigenous peoples may be reluctant to engage with these health researchers due to concerns that research under the control of outsiders to Indigenous communities will come to conclusions about Indigenous health disparities that stereotype, pathologize, and/or marginalize Indigenous peoples; be instrumental in rationalizing colonialist perceptions of Indigenous incapacity and the need for paternalistic control of Indigenous interests; deduce that Indigenous peoples are sick and incapable of self-care; and appropriate or not value traditional knowledge or cultural practices (Castellano 2004; Gracey and King 2009; Reading and Wien 2009; Smylie and Adomako 2009; Willows 2013; Adam and Smylie 2015). The dilemma for Indigenous communities with pressing health concerns is that they may feel compelled to engage with researchers who lack experience with research approaches and methodologies that are appropriate for an Indigenous research context such as being respectful of traditional knowledge, cultural practices and beliefs. There may be concerns that the approaches taken will not be inclusive of Indigenous perspectives, processes, and ways of learning/knowing; will not recognize colonization and exclusionary social policies as Indigenous health determinants; will not take a strength-based approach to research but rather one based on deficits and victim-blaming; and will not use approaches that recognize the potential trajectories of the social determinants of health across the life course (Bartlett et al. 2007; Reading and Wien 2009; Pigford et al. 2013).

4 The Right of Indigenous Peoples to Participate in Decolonizing Research that Improves Health and Well-Being

Decolonizing research is required that serves to restore order to daily living in conformity with ancient and enduring Indigenous values that affirm life (Castellano 2004; see also “Indigenist and Decolonizing Research Methodology and Using an Indigenist Framework for Decolonizing Health Promotion Research”). Table 1

Table 1 Aspects of life-affirming decolonizing research with Indigenous populations

Aspect of decolonizing research	Sample reference
Aims to create knowledge for social benefit	Castellano (2004), Gray and Opreescu (2015), Robertson (2016)
Follows a code of ethics based on rules of conduct which distinguish between acceptable and unacceptable research practices, and expresses and reinforces important indigenous social and cultural values	Castellano (2004), First Nations Centre (2007)
Addresses the hierarchical relation of power that privileges academic over local, indigenous knowledge by incorporating or honoring research methods and theories rooted in indigenous knowledge	Bartlett et al. (2007), Castellano (2004), Zavala (2013)
Includes indigenous elders or other keepers of cultural knowledge in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge	Castellano (2004), Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (2014)
Explicitly recognizes the right of indigenous communities and nations to be self-determined and self-governed in matters relating to their internal and local affairs	Castellano (2004)
Controlled by indigenous people, which overcomes the ineffectiveness of externally imposed and expert-oriented forms of research and helps to prevent the production of knowledge of little value to indigenous communities	Bartlett et al. (2007), Castellano (2004), Zavala (2013)
Use strength-based rather than deficit-based research approaches	Pigford et al. (2013)
When research involves communities, use a community-based participatory research approach whereby community members are equal partners in the research process with researchers from outside of the community	Bartlett et al. (2007), Castellano (2004), Castleden et al. (2012), LaVeaux and Christopher (2009), Pigford et al. (2013), Zavala (2013)
When working with communities, consider including a research partnership agreement “that represents a formal summary of rights, responsibilities and good faith between the parties entering into a partnership to jointly conduct research”	First Nations Centre (2007, p. 11)

outlines some aspects of such life-affirming decolonizing research. Indigenous peoples, according the United Nations Declaration on the Rights of Indigenous Peoples, have the right to maintain, control, protect, and develop their intellectual property over traditional knowledge. In Canada, Ownership, Control, Access, and Possession (OCAP[®]) is a registered trademark of the First Nations Information

Governance Centre (FNIGC)) (www.FNIGC.ca/OCAP) research principles offer a First Nations approach to research, and data and information management, which help to ensure First Nations aspirations towards self-determination and self-governance. These principles affirm that a First Nations community owns research information collectively (**Ownership**); is within its rights to seek control over all aspects of research and information management processes which impact it (**Control**); has access to the information and data about their community (**Access**); and can have physical control of research data (**Possession**) (First Nations Centre 2007).

Below, I expand on the practices and considerations for decolonizing and ethical research with Indigenous communities, using examples from Indigenous research frameworks, ethic guidelines developed for academic researchers working with Indigenous peoples in Canada and New Zealand, and research guidelines developed by Indigenous agencies or communities to ensure ethical research. The guidelines and frameworks are meant to ensure that research is ethical, culturally appropriate, collaborative, meaningful, and beneficial to Indigenous communities. Concerns about the implementation of some of these practices and considerations are outside the scope of this chapter to discuss in detail. For instance, there may be inconsistencies in ethical requirements between institutional review boards/academic research ethics boards and Indigenous review boards, lack of clarity about whether community self-determination is more important than individual autonomy in decisions about research participation, concerns that the rigidity of institutional review boards/academic research ethics boards requirements to “protect” Indigenous communities ironically undermines community self-determination, contested issues around academic freedom and research findings as intellectual property, and the expense and challenges of conducting community-based participatory research (Smith-Morris 2007; Ritchie et al. 2013; Angal et al. 2016; Brunger and Wall 2016).

5 Research Frameworks for Research with Indigenous Peoples: Examples from Canada

In Canada, several Aboriginal-specific frameworks for decolonizing research and health promotion activities exist that de-emphasize the focus on individual-level risk factors for disease and instead highlight the contributions of social and environmental conditions to the divergence in health status between Indigenous and non-Indigenous peoples. A process framework has been developed for Aboriginal-guided decolonizing research that privileges Indigenous ways of learning/knowing. It employs iterative, culturally based, and process-oriented methods (Fig. 1). It was reported that implementing this framework in research involving Métis and First Nations peoples with diabetes increased the efficiency and effectiveness of the research process (Bartlett et al. 2007).

Some Canadian frameworks use a social-ecological approach that recognizes that individuals are embedded within social, economic, and political systems that shape health behaviors and access to resources necessary to maintain health. The *Integrated Life Course and Social Determinants Model of Aboriginal Health* is a

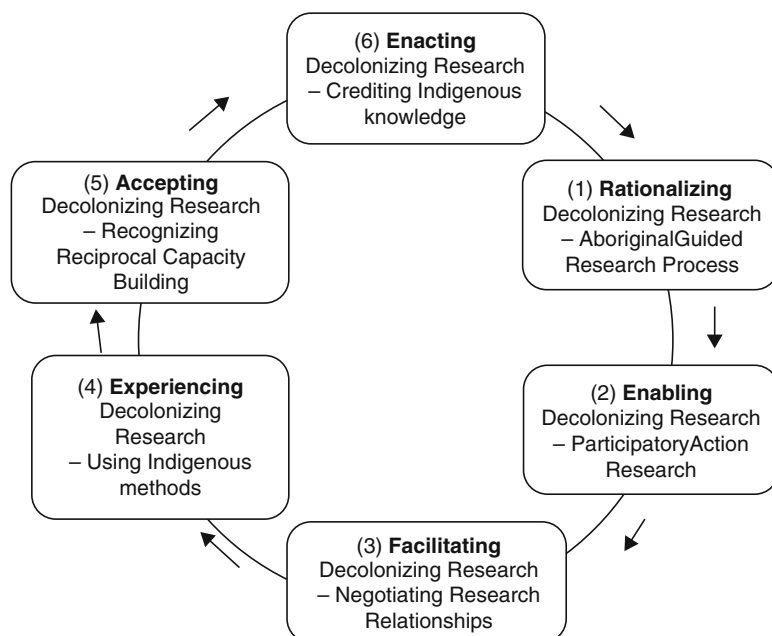


Fig. 1 Process framework for decolonizing research (Bartlett et al. 2007) (Reprinted from Social Science & Medicine, 65(11), Bartlett, J. G., Iwasaki, Y., Gottlieb, B., Hall, D., & Mannell, R. Framework for Aboriginal-guided decolonizing research involving Métis and First Nations persons with diabetes, pages 2371-2382, 2007, with permission from Elsevier)

population-focused conceptual framework for understanding the relationship between various health dimensions and the social determinants, categorized as proximal, intermediate, and distal. It also examines potential trajectories of health across the life course (Reading and Wien 2009). Not taking social-ecological factors into account can result in failed health interventions. This was the conclusion of a review of seven healthy weight interventions specifically aimed at First Nations or American Indian children and youth (Townes et al. 2014). Only two of the interventions included environmental or policy components that supported behavior change. The authors of the review concluded that the ineffectiveness of the interventions to reduce obesity or overweight was because structural factors in the social, economic, and physical environments where the Indigenous children and youth lived prevented them from making the behavioral changes required to have a healthy body weight.

The *Integrated Life Course and Social Determinants Model of Aboriginal Health* provides an analytical guide to explore the relationships between the social determinants of health (SDoH) and health outcomes among First Nations people living off-reserve as captured in the 2012 national Aboriginal Peoples Survey (Rotenberg 2016). SDoH were examined using the categories of the model as follows: proximal (health behaviors, physical and social environment); intermediate (community infrastructure, resources, systems, and capacities); and distal (historic, political, social,

and economic). This approach permitted the researcher to determine which SDoH assessed at the three levels had the greatest impact on the likelihood of a First Nations person having a chronic condition, poor or fair self-rated general health, or poor or fair self-rated mental health. For example, when proximal determinants were examined, those related to negative health outcomes were smoking, obesity, living in a dwelling where major repairs were needed, having less than a high school education or being unemployed, living in a low-income household, or experiencing household food insecurity. The compounding effects of having multiple points of social disadvantage on health were explored by examining the exacerbating effects of intersecting SDoH. The results showed that the likelihood of reporting any of the three negative health outcomes increased as the number of social determinants of poor health increased. It was evident from study findings that health behaviors as well as environmental and social conditions impact the health outcomes of First Nations people living off-reserve, thus individual, family, and community interventions are all required to improve health (Reading and Wien 2009).

Willows et al. (2012) developed a *Socioecological framework to understand weight-related issues in Aboriginal children* that highlighted the need to understand childhood obesity within the context of inequities in the social determinants of health (Fig. 2). The framework focuses on the many environments at different times in childhood that influence an Aboriginal child's weight status, including prenatal, sociocultural, family, community, and policy environments. The framework highlights historical and ongoing factors related to children having an unhealthy body weight, including colonization by Europeans, dispossession of Aboriginal peoples from their traditional lands, and assimilation policies which influence all other socioecological levels (i.e., individual; intrapersonal; community, home, sociocultural; built environment; and society).

6 Institutional Research Guidelines: Canada and New Zealand

Health research ethics guidelines for Indigenous peoples should deal minimally with issues such as the nature of the relationship between the researcher and the research participant; ownership of and access to data; conflict of interest; consent to research; privacy and confidentiality; and measures to preserve human dignity (First Nations Centre 2007). Various guidelines for research with Indigenous peoples exist in Australia, Canada, New Zealand, and the United States. For example, in Australia there are ethical guidelines for research involving Aboriginal and Torres Strait Islander People, which were last revised in 2004, that indicate that research must be conducted in an ethical and culturally safe and appropriate manner as to protect the health, safety, and well-being of Aboriginal and Torres Strait Islander peoples and their communities (National Health and Medical Research Council 2016). The Australian Institute of Aboriginal and Torres Strait Islander Studies (2012) also created *Guidelines for Ethical Research in Australian Indigenous Studies* to ensure that research with and about Indigenous peoples follows a process

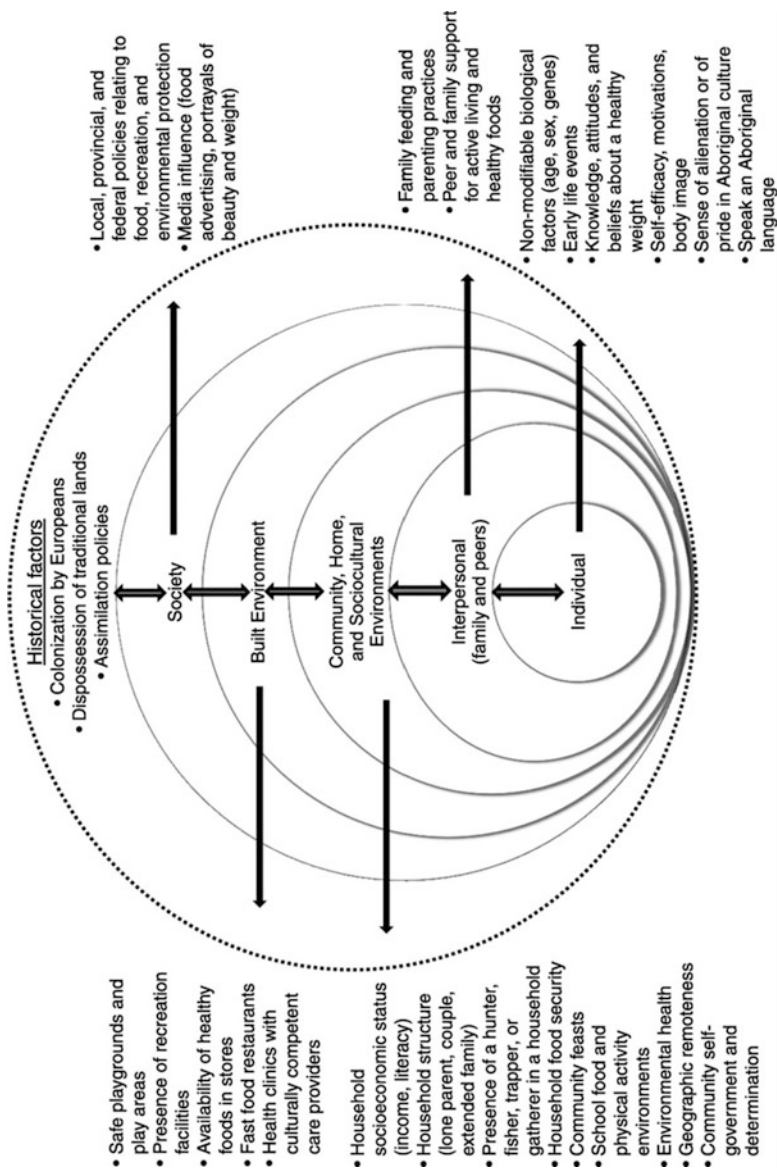


Fig. 2 Ecological model for understanding obesity in children, which illustrates the reciprocity among levels that influence active living, the consumption of healthy foods, and weight status, and which recognizes that historical factors encompass and influence all ecological levels (Willows et al. 2012)

of meaningful engagement and reciprocity between the researcher and the individuals and/or communities involved in the research. In the United States, there are various codes of ethics and guidelines for researchers and scholars working on projects related to Native Americans, Alaska Natives, or Native Hawaiian peoples. However, as recently as 2009, concerns were expressed that issues such as tribal sovereignty were still not adequately protected by current legislation (Sahota 2009). The website of the National Congress of American Indians' Policy Research Center (<http://www.ncai.org/policy-research-center/initiatives/research-regulation>) provides resources to support tribes and American Indian and Alaska Native communities working to develop research oversight processes and policies. For the sake of brevity, only health research ethics guidelines from Canada and New Zealand will be described in this chapter.

6.1 Canada: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans: TCPS 2

Institutions eligible to receive funding from Canada's three federal research agencies – the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada – must agree to adhere to the Tri-Council Policy Statement: Ethical conduct for research involving humans (known as the TCPS 2) as a condition of funding (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada 2014). Research Ethics Boards at Canadian Universities must ensure the application of the TCPS 2 to human research. The TCPS 2 was last revised in 2014. Chapter 9 is titled "Research Involving the First Nations, Inuit and Métis Peoples of Canada." It is designed to serve as a framework for the ethical conduct of research involving the Indigenous peoples of Canada, but is not intended to overrule or replace ethical guidance offered by Aboriginal peoples themselves. An online tutorial is available to help researchers to understand Chapter 9 (Government of Canada n.d.).

It is intended that research that follows Chapter 9 guidelines will reflect Aboriginal worldviews, and will benefit Aboriginal peoples or communities. The chapter offers guidance on how to respect a community's cultural traditions, customs, and codes of practice. For example, Article 9.15 relates to the recognition of the role of Elders and other knowledge holders in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge. Aboriginal Elders are often the most knowledgeable persons about Indigenous cultural rules and traditions, perceptions of physical and spiritual reality, the teaching and practices of ceremony, and the nuances of meaning in Indigenous languages.

Chapter 9 interprets in nine articles how the value of respect for human dignity and the core principles of Respect for Persons, Concern for Welfare, and Justice discussed in other chapters of the TCPS 2 apply specifically to research involving Aboriginal peoples in Canada. For example, Respect for Persons in an Aboriginal

context goes beyond securing free, informed and ongoing consent of participants. It also includes obligations to maintain, and pass on to future generations, knowledge received from ancestors. The principle of Concern for Welfare goes beyond considerations for individual well-being to considerations for the welfare of the Aboriginal community to which participants belong. Justice may be compromised when an imbalance of power prevails between researchers and participants. With research involving Aboriginal peoples, the social, cultural, or linguistic distance between participants and researchers may be significant, thus, engagement between the community involved in research and the researchers, initiated prior to recruiting participants and maintained over the course of the research, is recommended as an integral aspect of ethical research.

The ethics review process at the University of Alberta (UAlberta) where I work in Canada will be used here as an example of how Chapter 9 of the TCPS 2 is ensured. UAlberta requires that all research involving humans conducted by staff or students affiliated with UAlberta, or involving UAlberta resources, must be reviewed and approved by one of UAlberta's Research Ethics Boards before the research starts. The Boards ensure that research projects involving human participants, identifiable data, and/or human biological material meet the requirements of the TCPS 2 and UAlberta policy, as well as any applicable provincial, federal, and other legislation and regulations. Research with Aboriginal peoples conducted by UAlberta staff or students must include community engagement to ensure that Aboriginal peoples have a role in the research that affects them. As of 2016, applicants seeking ethics approval for research involving Aboriginal peoples are required to answer questions relating to topics such as obtaining consent from Elders, leaders, or other community representatives; details about whether property or private information belonging to the group as a whole is studied or used; details about whether the research is designed to analyze or describe characteristics of the group; details about whether individuals are selected to speak on behalf of or otherwise represent the group; information regarding consent; information about the access, ownership, and sharing of research data with communities; information about how final results of the study will be shared with the participating community; and, the nature of research agreements.

Appropriate protocol must be followed when researchers seek the advice of Elders and when they acknowledge the contributions of Elders to their research. Researchers may be unfamiliar with these protocols. The Council of Aboriginal Initiatives at UAlberta has therefore published a document related to Elder protocol and guidelines to help researchers meet the guidelines of Chapter 9 of the TCPS 2 (Council of Aboriginal Initiatives, University of Alberta [2012](#)).

6.2 Ethical Guidelines for Health Research with Māori in New Zealand

The document *Guidelines for Researchers on Health Research Involving Māori* (version 2) was created in 2010 by the Māori Health Committee (MHC) of the

Health Research Council of New Zealand (HRC) (Health Research Council of New Zealand 2010). Its aim is to assist researchers who have received Health Research Council funding to undertake biomedical, public health, or clinical research involving Māori participants or research on issues relevant to Māori health. The intent of the Guidelines is to help develop research that contributes to Māori health development whenever possible, and partnerships between health researchers and Māori communities or groups on issues important to Māori health. The Guidelines state that the principles of partnership and sharing implicit in the Treaty of Waitangi, New Zealand's founding document which describes principles for a partnership between the government and Māori, should be respected by researchers and, where applicable, should be incorporated into all health research proposals. Three principles are particularly relevant in the proceedings and processes of ethics committees relating to research with Māori. There is the principle of Partnership, which means working together with iwi (tribes or nations that form the structure of Māori society), hapu (clans or descent groups within each iwi), whanau (extended families or family groups), and Māori communities to ensure Māori individual and collective rights are respected and protected. There is the principle of Participation, meaning that Māori will be involved in the design, governance, management, implementation, and analysis of research. There is the principle of Protection, meaning that the research process will actively protect Māori individual and collective rights, Māori data, and Māori culture, cultural concepts, values, norms, practices, and language.

The Guidelines require that researchers conducting research on a Māori health issue and/or involving Māori as participants need to start initial consultation and conversations with Māori before putting the research proposal together. Ongoing consultation throughout the research is urged. Researchers must acknowledge Māori ways of knowing and conducting research. When a project involves Māori within a given geographical area as participants, researchers must contact local Māori representative organizations, advise them of the nature of the intended study, and invite their comments and/or involvement. Research must not desecrate or contribute to the erosion of Māori cultural values (see also ► Chaps. 87, “Kaupapa Māori Health Research,” and ► 88, “Culturally Safe Research with Vulnerable Populations (Māori”).

7 Guidelines for Health Research Developed by Indigenous Communities or Agencies

Many Indigenous communities and organizations in Australia, Canada, New Zealand, and the United States have taken up the challenge of conducting and monitoring research to ensure local involvement. Some Indigenous communities have developed their own codes of research conduct (e.g., Kahnawake Schools Diabetes Prevention Project 2007; Pigford et al. 2013), and Indigenous organizations have formed their own ethic review panels and boards, which function separately from University Institutional Review Boards/Research Ethics Boards (e.g., Sahota 2009; Harding et al. 2012; Angal et al. 2016). The existence of community codes of

research conduct as well as independent Indigenous ethics panels and boards means that a single research project may require multiple authorizations to proceed depending on the nature, scope, and location of the research activity.

Space does not permit a review of the numerous research guidelines developed independently by Indigenous agencies and communities that outline local principles of research conduct. Typically, these guidelines provide ethical considerations regarding local perspectives and values, provide for optimal community oversight of the research, and help ensure that research addresses community concerns and expectations. They may focus on ensuring that research adheres to values that University Institutional Review Boards/Research Ethics Boards might overlook such as the interdependent relationship between humans and natural elements, recognizing community as a unit of identity, awareness that any particular event or phenomenon functions as part of a larger whole, or safeguarding cultural and intellectual heritage (Harding et al. 2012; Brunger and Wall 2016). For example, all research occurring in the predominantly Inuit-occupied territory of Nunavut in northern Canada is licensed by the Nunavut Research Institute in accordance with the Nunavut's Scientists Act, which helps ensure that research is collaborative and addresses Nunavut's needs and priorities (Nunavut Research Institute 2015).

8 Building Capacity to Do Ethical Research with Indigenous Peoples

Indigenous researchers trained as Western health professionals but who are grounded in their Indigenous identities are an important, but small, cadre of researchers. Australia, Canada, New Zealand, and the United States all have too few Indigenous scholars available to conduct all of the health research required with Indigenous peoples. This under-representation among the professoriate means that training to undertake ethically conducted Indigenous health research is required for non-Indigenous scholars. Researchers who are not Indigenous need to develop a capacity to bracket Western research paradigms and assumptions in order to become knowledgeable about Indigenous paradigms (Bartlett et al. 2007). Even Indigenous scholars conducting research can benefit from formal training in decolonizing research if they have become alienated from their culture, if they do not hold traditional Indigenous world views, or if they are not familiar with how to conduct such research.

Health research with Indigenous peoples that respects Indigenous self-determination, and is safe, ethical, and useful for participants, requires increased capacity among Indigenous and non-Indigenous peoples alike. Researchers regardless of their indigeneity require, in addition to conventional health research training that emphasizes a biomedical model of illness and disease, training that focuses on understanding the SDoH in relation to disease occurrence and patterns. Conventional health research often dictates the use of positivism as a scientific paradigm, whereby researchers, in their search for an ultimate reality, are to be value free and objective in their approach to research, and detached from research participants to ensure that

researchers and their research “subjects” do not influence each other (see ► [“Indigenous Statistics”](#)). While there is value in this paradigm, research with Indigenous peoples may require a more interpretivist approach which is receptive to capturing meanings in human interaction and making sense of what is perceived as reality (Carson et al. 2001).

As stated already in this chapter, many of the health inequities experienced by Indigenous peoples are the result of historic and current national and local policies designed to eliminate and/or assimilate Indigenous people. Research that is designed to address and eliminate the health and socioeconomic inequities faced by Indigenous peoples requires researchers to have knowledge of history, policy, health determinants, ethics, and Indigenous rights issues. Researchers must value the lived experience of participants by focusing on the meaning and interpretation that individuals place on events (Liamputtong 2013, 2017). Researchers must have an attitude of mutuality and openness, self-awareness, and self-reflexiveness; facilitative skills in interpersonal and group settings; and, a willingness to produce knowledge to empower a group of people, and to work authentically in collaboration with people to improve their lives (Liamputtong 2010, 2013). The research should be designed to coproduce culturally respectful, relevant, and empowering knowledge (Castleden et al. 2012). Healthcare training programs designed to produce researchers that can work in an Indigenous context should have content related to how structures of power rooted in colonialism continue to create health inequities and how an individual’s own experiences of privilege and oppression affect their practice (Beavis et al. 2015). The acceptance by the professoriate of research that uses Indigenous methodologies to produce transformative change may require a “decolonizing” of the academy (Robertson 2016; see ► [Chap. 15, “Indigenist and Decolonizing Research Methodology”](#)).

There are numerous examples of programs and workshops designed to build capacity among Indigenous peoples to conduct research or to partner with outsiders to conduct research. For the sake of brevity, below I provide some examples of Canadian and American programs that seek to improve the ability of health researchers to work with Indigenous peoples or in Indigenous communities, or that aim to educate Indigenous peoples about research topics. Some of the programs offer travel scholarships or tuition waivers to Indigenous applicants.

8.1 Institute on the Ethics of Research with Indigenous Peoples

Carleton University in Canada launched the Institute on the Ethics of Research with Indigenous Peoples (CUIERIP) in June of 2015 (<https://carleton.ca/aboriginal/>). CUIERIP is a week-long summer institute to equip Indigenous and non-Indigenous researchers with tools to implement ethical practices when working with First Nations, Inuit and Métis communities, or conducting research on traditional Indigenous territory. Its scheduling coincides with the spring term session of courses for Carleton’s Masters degree concentration in Indigenous Policy and Administration. CUIERIP is intended for a diverse audience, including academic

researchers, research ethics board members, graduate students, First Nations, Inuit and Métis community members, and researchers and representatives from governmental and nongovernmental organizations. Participants learn in a collaborative environment and are led by Carleton faculty, research ethics professionals, and Indigenous and non-Indigenous community-based researchers with expertise in research ethics, community engagement, and research design and review. Participants work together in small groups using case studies to work through the ethical issues involved in community engagement plans and research agreements.

8.2 Centre for Excellence in Indigenous Health

The Centre for Excellence in Indigenous Health in the Faculty of Medicine at the University of British Columbia in Canada exists to support and develop Aboriginal health programs, curriculum, research, and advocacy with Aboriginal communities and partners on local, national, and international levels (<http://health.aboriginal.ubc.ca/education/>). It offers an undergraduate course called Topics in Indigenous Health: A Community-Based Experience (<http://health.aboriginal.ubc.ca/education/ihhs-408/>). This 4-week practice-based Indigenous health elective has health sciences students live and work with students from other health disciplines within an Indigenous community in the Province of British Columbia. The course objectives seek to foster increased awareness of the core principles required to do community-based participatory research with Indigenous communities such as gaining an understanding of and respect for Indigenous perspectives on health and wellbeing; understanding, acknowledging, and exploring the implications of specific processes of colonization and related social policies for the health of Indigenous peoples; examining and identifying patterns of health and illness from multiple perspectives: epidemiology, interdisciplinary health, community, and Indigenous knowledge; and, demonstrating respectful communication with Indigenous peoples.

8.3 Community-Based Research and Evaluation Certificate Program

The UAlberta in Canada offers the embedded graduate Community-Based Research and Evaluation (CBRE) Certificate Program (<https://www.extension.ualberta.ca/study/community-engagement-studies/cbre/>). It is designed for graduate students who seek to develop their capacity to participate in and lead community-based research and evaluation. Though not specifically designed to train students to do research and evaluation in Indigenous communities, students can choose to partner with an Indigenous community and Indigenous community mentor if they are interested in CBRE in Indigenous contexts.

All students in the certificate program must take a graduate level course called An Introduction to CBPR. This course has historically included some guest lectures by researchers working in Indigenous communities or Indigenous community members participating in CBPR with academic researchers. In consultation with a CBRE

Advisor and their graduate supervisor, students are additionally required to take graduate level-courses in program planning and evaluation; quantitative research methods; and qualitative research methods. Through coursework, students develop an understanding of CBRE concepts, program planning and evaluation, and a variety of quantitative, qualitative, and/or mixed methods. The program has a mandatory experiential component in a community setting to apply the concepts and methods learned through their course work including relationship building and maintenance; political sensitivity; development of a partnership agreement; participation in day-to-day, project-management duties; participation in partnership decision-making; participation in the development of a specific project within a partnership; and, development and/or implementation of a process evaluation of the partnership. A Community Mentor and the CBRE program Experiential Learning Coordinator jointly supervise the CBRE community experience which is a minimum of 156 h.

8.4 Master of Public Health: Native Hawaiian and Indigenous Health Specialization

In an effort to address the disparities faced by Native Hawaiians and other Indigenous Peoples, the University of Hawai'i, Office of Public Health Studies, has a specialization in Native Hawaiian and Indigenous Health within the Master of Public Health degree. Both of the professors in the Native Hawaiian and Indigenous Health specialization are Indigenous scholars. This specialization is designed to prepare students with the public health skills and training necessary to serve Indigenous People globally and assist in addressing their health and wellness needs by contextualizing health determinants within historical and political frameworks. It provides extensive training in culturally sensitive research ethics which is critical for safely and effectively implementing public health research and programs aimed to address and eliminate the inequities faced by Indigenous People. Students enrolled in the specialization are required to take advanced level training in Indigenous health policy, ethics, and research design. The curriculum integrates Indigenous Public Health Competencies with traditional competencies to help build a stronger, more effective public health workforce in Native Hawaiian and Indigenous communities (Tualii et al. 2013). Students participate in ongoing research and practice programs with Indigenous communities through a practicum assignment (<http://manoa.hawaii.edu/publichealth/specializations/native-hawaiian-and-indigenous-health>).

8.5 Community Mobilization for Healthy Lifestyles and Diabetes Prevention Training Program

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is one of the longest-running community-based health research projects in Canada. It has been in operation since 1994. It occurs in the Kanien'kehàka (Mohawk First Nations) community of Kahnawake. The community offers a KSDPP Training Program in Diabetes

Prevention to enable and empower participants to begin or enhance a diabetes prevention or wellness program in their community based on the experiences of the KSDPP (http://www.ksdpp.org/elder/training_program.php). The Community Mobilization for Healthy Lifestyles & Diabetes Prevention Training Program shares the successful experiences of the health promotion model of KSDPP with Indigenous community organizations and individuals working with Indigenous communities (<http://www.ksdpp.org/media/brochure.pdf>). These multiday workshops provide information, facilitate discussion, and engage participants to plan community actions for healthy lifestyles and diabetes prevention. The program provides participants with skills that will help them to do research in their own communities or negotiate CBPR by providing them with an understanding of the theoretical background for successful healthy lifestyles programming; identifying community values in relation to healthy lifestyles and diabetes prevention; the importance of teamwork; how to build a Community Advisory Board (CAB), identify potential CAB members, and the nature and activities of CAB volunteers; conducting an environmental scan to identify key goals, objectives, and strategies for the planning and successful implementation of healthy lifestyles and diabetes prevention planning; different types of community intervention activities, the steps in planning activities, the development of community activity calendars, and activity evaluation; and, developing a dissemination program to promote healthy lifestyles and diabetes prevention.

8.6 Summer Research Training Institute for American Indian and Alaska Native Health Professionals

The 2016 Summer Research Training Institute for American Indian and Alaska Native Health Professionals in the United States was hosted by the Northwest Portland Area Indian Health Board and the Center for Healthy Communities at Oregon Health & Science University (http://www.npaihb.org/images/training_docs/NARCH/2016/2016_SI_Brochure_Final.pdf). The curriculum of this 3-week course was designed to meet the needs of professionals who work in diverse areas of American Indian and Alaska Native health – from administrators to community health workers, physicians, nurses, researchers, and program managers. It emphasizes research skills, program design, and implementation.

9 Conclusion and Future Directions

This chapter discussed how States, academic institutions, and Indigenous groups can support ethical research with Indigenous peoples, communities, and nations located in Australia, Canada, New Zealand, and the United States. It also discusses why they should do so. Ideally, ethically conducted research would be decolonizing research that leads to self-determination. It would empower Indigenous people through the process of constructing and using their own knowledge.

Unfortunately, there is reluctance on the part of some academic researchers and Indigenous communities to coparticipate in health research. Indigenous peoples may believe that they will not benefit from the research, or worse, that they will come to harm by participating in health research. Both Indigenous community members and health researchers perceive barriers to doing ethical research. This hesitancy to engage in research means that the research that is needed in Indigenous communities for improved health and well-being is not always being done, or is not being done well. To help ensure that beneficial research occurs, community members need to be provided with workshops and training sessions that will teach them how to negotiate with health researchers from outside of their communities, let them know their rights as research participants, and build their skills to conduct their own research or to engage in CBPR with outsiders. Research undertaken by non-Indigenous researchers can lead to improvements in the health status of Indigenous people provided that researchers have appropriate ethical guidelines to follow and training opportunities that offer guidance on Indigenous ways of knowing, the SDoH, strength-based research approaches, CBPR, and how to engage in culturally appropriate ways with Indigenous peoples. Researchers wanting to pursue a specialization in Indigenous health research need support from academic leadership and funding agencies to be successful in their endeavor.

Although conducting ethical research in Indigenous communities offers challenges to both academic and community partners, there are many community, academic, and personal rewards and benefits to adhering to the additional ethical standards and research procedures required to do research well in an Indigenous context. I suggest more understanding of the following research areas and topics to broaden the support for engaged scholarship between researchers and community members undertaking ethical research related to Indigenous health.

- Richly detailed case studies that demonstrate how and why ethical research with Indigenous peoples increases both individual and community-level self-determination, and consequently, increases Indigenous peoples' perceived control over health.
- Examples of how to best support Indigenous health research that champions democratic empowerment, whereby communities and community members assess their own interests and make decisions on how to see these interests put into action.
- Research to discover if the acquisition of new skills and knowledge by Indigenous community members in relation to conducting health research, or participating in health research, results in the ability of members to positively influence community change.
- The development of research models that incorporate an understanding of how Indigenous communities can combine the diverse types of research knowledge (e.g., biomedical) emanating from community-based participatory research with the practical and cultural knowledge of community members to create positive health outcomes, by influencing the social determinants of health, the social policy process, and important policy issues (Bryant et al. 2007).

- Examples of how academics can be supported both financially and institutionally to conduct ethical health research with Indigenous peoples and communities that emphasizes social change and positive health outcomes as an endpoint.
- Descriptions from health researchers of how they have benefited professionally and personally from undertaking ethical research in Indigenous communities.
- Descriptions from Indigenous community members of how they have benefited from undertaking ethical research with health researchers.

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Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds 107

Anna Ziersch, Clemence Due, Kathy Arthurson, and Nicole Loehr

Contents

1	Introduction	1872
2	A Note on Terminology	1873
3	Research Design and Methodologies	1874
3.1	Participatory Research Methodologies	1875
3.2	Quantitative Research Methods	1876
3.3	Qualitative Research Methods	1877
4	Research with Children and Young People	1879
5	Data Collection	1880
5.1	Building Rapport and Cross-Cultural Competency	1881
5.2	Sampling Issues	1881
5.3	Interpreting and Translation	1882
6	Ethical Considerations	1882
7	Advocacy	1885
8	Conclusion and Future Directions	1885
	References	1886

Abstract

This chapter outlines issues to be considered when working on health and other research with people from asylum seeker or refugee backgrounds in countries of resettlement. The chapter highlights the utility of a Social Determinants of Health framework and outlines the importance of ethical research, which balances the considerations of formal ethics committees by ensuring that the voices of the most

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1871

vulnerable people within this population are able to be heard. In addition, the chapter highlights the need to facilitate the full participation of people with asylum seeker and refugee backgrounds, including in the governance structures of the research project and initial research design, in order to ensure that the outcomes of the research are relevant and address community needs and concerns. The chapter also outlines appropriate methodologies, including emerging and innovative research methods such as visual scales, photovoice, photo-language, and digital storytelling, as well as discussing the ways in which these data collection methods contribute to high quality quantitative and qualitative data. Finally, the chapter also covers the challenges of working cross-culturally such as the use of standardized scales and interpreting and translation, and the need to ensure that research is culturally appropriate, consultative, and meaningful.

Keywords

Refugee · Asylum seeker · Social determinants of health · Participatory approaches · Ethics

1 Introduction

The number of refugees and asylum seekers worldwide currently stands at the highest level since World War II, with estimates of over 60 million people displaced or seeking refuge (UNHCR 2015). This group of people face a disproportionate burden of mental and physical ill health, due to issues such as a lack of infrastructure or health systems in countries of origin, frequently unequal access to healthcare in resettlement countries, and the ongoing impact of war and trauma (Schweitzer and Steel 2008). In addition, people with asylum seeker or refugee backgrounds face a range of complex and interplaying challenges when arriving in a resettlement country. These include access to education, difficulty finding employment, problems finding appropriate housing, disrupted social and family networks, and barriers to health service access. As such, and given the increasing numbers of people who are displaced or seeking refuge, it is critically important that there is empirical research into the health and well-being of this vulnerable group of people (Ellis et al. 2007; Hugman et al. 2011).

The World Health Organization (WHO) defines (1948, p. 100) health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” WHO (2014) also defines mental health as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.” These broader notions of health and well-being are particularly important in planning and conducting research with refugees and asylum seekers as they allow for an inclusion of different cultural understandings of what constitutes health and/or well-being and extends the focus away from narrow disease or illness notions of health (Hugman et al. 2011).

This chapter draws on a Social Determinants of Health (SDoH) framework to consider best practice in health research with refugees and asylum seekers. The social determinants of health are defined by the World Health Organization as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems” (WHO 2016). Drawing on a SDoH approach focuses the research “lens” onto the range of factors impacting on refugee and asylum seeker health and well-being ranging from the structural determinants of socioeconomic and political context and social position through to the material circumstances that people live in, psychosocial factors, behaviors, and biological factors, as well as the health system itself (Solar and Irwin 2010; Liamputtong et al. 2012). Improving refugee and asylum seeker health requires action at all these levels and research has an important role to play across this endeavor (McMichael 2016).

While research into refugee and asylum seeker health is vital, many previous researchers working in this area have documented a range of challenges to research with refugee communities, including the ethical challenges of working with vulnerable populations, and methodological challenges relating to cross-cultural research, valid research tools, and equivalency of meaning when considering data (Ellis et al. 2007; Due et al. 2014). As argued by Ellis et al. (2007, p. 460), research with refugees and asylum seekers “demands that researchers think beyond standard recommendations.” While there are existing research guidelines, such those pertaining to human research ethics, that outline the importance of rigorous and ethical research, there is a need to critically examine these documents when working across cultural and ethnic divides, and when the research concerns a new or emerging social or community issue (Ellis et al. 2007). In this chapter, we highlight a range of considerations for undertaking health-related research with refugees and asylum seekers including research design, data collection, and ethical considerations and the role of advocacy.

2 A Note on Terminology

The 1951 United Nations Refugee Convention defines a refugee as “a person who is outside his/her country of nationality or habitual residence; has a well-founded fear of persecution because of his/her race, religion, nationality, membership in a particular social group or political opinion; and is unable or unwilling to avail himself/herself of the protection of that country, or to return there, for fear of persecution” (UNHCR 1967, p.14). Asylum seekers can be defined as people who are displaced and likely seeking refugee status, but who have either not have their claims reviewed or have not yet have them approved. While both refugees and asylum seekers face a range of challenges, it is important to note that asylum seekers are likely to experience added difficulties in resettlement countries, relating to issues such as experiences of detention, visa restrictions, and restrictions on

employment and education (McMaster 2006). Despite this extra vulnerability, most research in this area focuses on refugee health rather than asylum seeker health. In this chapter, we similarly refer to “refugees and asylum seekers” for ease of expression, but acknowledge the heterogeneity in this population, the risks of assuming that all asylum seekers or refugees experience similar challenges, and also that some people from refugee backgrounds may not identify themselves as refugees once they have resettled. We deal with this issue throughout the chapter, where appropriate.

3 Research Design and Methodologies

Numerous researchers (e.g., Ellis et al. 2007; Block et al. 2012; Hanza et al. 2016) have highlighted that research with refugees and asylum seekers can be challenging methodologically. Not least of the issues that may be presented is that of community engagement and involvement in the research process. Moreover, Hanza et al. (2016) argue that this is particularly the case in health research, where refugees or asylum seekers are frequently either completely overlooked, or at least under-represented, in clinical trials or other forms of research concerning health and well-being. As a result, many of the conclusions drawn from “mainstream” health research may not be applicable to refugee or asylum seeker populations, leading to a dangerous gap in knowledge. This gap is compounded by the fact that the results of mainstream research are unlikely to be generalizable to refugee and asylum seeker communities given the diversity of experiences and compounded risk factors these groups face. As such, it is important that researchers take up the challenges to include refugees and asylum seekers in their research protocols, and design their research accordingly. Furthermore, and as outlined elsewhere (Pittaway and Bartolomei 2003; Ellis et al. 2007; Hugman et al. 2011) and above, it is important that research designs take into account community understandings of the constructs under consideration in the research, including physical or mental health. Correspondingly, a central aspect of research design with refugee or asylum seeker communities is that of close community collaboration to ensure that the research results will be valid.

In relation to theory, previous research with refugees and asylum seekers has spanned a broad and diverse range of theoretical frameworks, clearly depending on the research aims and questions of specific research. Here, we argue that whatever theoretical orientation is used in research, there are two important considerations. First, theories should not constrain research such that the meanings of concepts or constructs are limited and do not take into account cultural understandings. This is particularly important with regard to health research, as outlined throughout this chapter. Secondly, and relatedly, research should be designed with close collaboration with community members. Below, we discuss participatory research methodologies as one example of how research can centrally involve community members.

3.1 Participatory Research Methodologies

Participatory research methodologies (see Pittaway and Bartolomei 2003; McMichael et al. 2014; Higginbottom and Liamputtong 2015 for an overview; see also ► Chaps. 17, “Community-Based Participatory Action Research,” and ► 100, “Participatory and Visual Research with Roma Youth”) are well suited to research designs in the area of refugee health and well-being (Hanza et al. 2016). Participatory research designs foreground community knowledges and promote close collaboration between researchers and communities by placing community leaders at the center of the research structure such that the research becomes collaborative rather than “top down” (Hugman et al. 2011). Participatory research methodologies aim to work side by side with community leaders and members in all elements of research design, including defining research questions, the choice of research methods, the conduct of the research, and the application of research findings and outcomes (Pittaway and Bartolomei 2003; Block et al. 2012; Due et al. 2014; Higginbottom and Liamputtong 2015; Hanza et al. 2016). As such, participatory research methodologies work to bridge the gap between science and practice through community engagement and social action to decrease health disparities. Such designs employ strategies to reduce power imbalances, encourage knowledge translation, and incorporate community perspectives and theories into the research (Wallerstein and Duran 2006). This close community collaboration at each research stage goes some way to overcoming some of the challenges noted above, particularly in relation to ensuring cultural relevancy and correctly interpreting results.

Importantly, a range of methods and theoretical standpoints can be used within an overarching participatory research framework, although grounded theory or deductive frameworks are arguably best suited given the focus on community knowledges (see Charmaz 2014; Corbin and Strauss 2015; see also for an overview of grounded theory). Nevertheless, participatory research may adopt an empirical, theory-driven methodology, with previous health research with refugees and asylum seekers focusing heavily on trauma theory (Schweitzer and Steel 2008). However, regardless of the epistemological stance taken, participatory research methodologies with refugee and asylum seeker populations should be flexible in their approach, in that the sociopolitical situation facing many refugees is also flexible and likely to change during the course of the research itself. As argued by Schmidt (2007), such highly charged political and social contexts mean that environmental situations often lead to methodological constraints, and research cannot proceed without taking into account these contexts. For example, the health focus of the research may be heavily influenced by sociopolitical change during the research (e.g., the start or end of conflict), and thus, a narrow focus on only individual factors may overlook important predictors of health and well-being.

This engagement of refugees and asylum seekers is vital in research concerning health and well-being, given the culturally and socially contingent definitions of these terms. Correspondingly, research in this area should be collaborative and take

into account the role of SDoH in health outcomes. This is especially pertinent for refugees and asylum seekers, since issues such as employment, education, housing, language, and community networks and the broader sociopolitical elements that influence them have all been previously shown to be closely related to health outcomes for this population.

3.2 Quantitative Research Methods

Quantitative research tools (such as standardized or validated physical or mental health scales) provide important information about the health of refugee and asylum seeker communities, particularly since the use of such tools allows comparison to other community groups or previous research outcomes (Schweitzer and Steel 2008; see also the ► [Chap. 63, “Mind Maps in Qualitative Research”](#)). However, standardized instruments measuring mental or physical health should be used with caution in research with refugee and asylum seeker populations. This is particularly the case since instruments may not be validated for the populations under consideration, leading to misunderstandings or inaccurate conclusions on the basis of the results (Ellis et al. 2007). Indeed, there is a dearth of appropriately validated instruments for measuring health and well-being in refugee populations, including children (Ehnholt and Yule 2006). In addition, the use of standardized tools such as mental or physical health measures may obscure cultural understandings of health and illness, such that individual scores on their own may provide little insight into the actual experiences of research participants themselves (Schwietzer and Steel 2008). This issue is compounded by the fact that a few health or mental health measures take a SDoH approach. Therefore, the sole use of such measures may obscure more culturally relevant understandings of aspects of health or the impact of particular factors on health outcomes (such as the impact of housing, employment, education, or family relationships). Correspondingly, quantitative methods may be best used side-by-side with qualitative methods, in order to ensure that the data gained from quantitative scales may be informed by qualitative work that provides insight into cultural understandings and knowledge through which to interpret the results (Gifford et al. 2007; Block et al. 2012).

Where quantitative methods such as surveys or standardized scales are used, it is important that these are translated and back-translated into first languages (or languages in which research participants are fluent) in order to ensure equivalency of meaning of questions, particularly if the research involves collecting data from diverse participants. Nevertheless, even such translation should be used with caution, particularly in the case of research with cultures with oral-based methods of communication, where direct translation of English text may obscure nuanced meanings and understandings (Ellis et al. 2007; Liamputtong 2010). If appropriate, a growing body of research includes the use of visual scales in quantitative measures – such as “smiley faces” ranging from very unhappy through to very happy – for questions that ask about happiness or satisfaction (Due et al. 2014). However, again, consideration should be paid to the impact that the use of such scales has on the original validity of the scale in question (e.g., in relation to the

number of points on the original Likert scale and the associated scoring procedures). The use of such scales should also take into account cultural norms around portraying the human face.

One final issue of importance in quantitative research lies with ensuring that the sample used in the research is sufficiently representative of the population under consideration to meet standards for generalizability typically held in quantitative research (Jacobsen and Landau 2003). For example, in many countries of resettlement there is limited data concerning new arrivals, and thus statistics concerning the population may be difficult to obtain (Spring et al. 2003; Ellis et al. 2007), meaning that it may be hard to recruit a sufficiently stratified sample (Vigneswaran and Quirk 2012). Attention should also be paid to the specific cultural, ethnic, and linguistic background of participants when recruiting from key community leaders who may only have access to particular groups of people (Ellis et al. 2007). Nevertheless, the inclusion of refugee participants is central to research designs in this area, and clear recruitment strategies should be in place to ensure that this occurs. This issue is discussed further later in the chapter.

3.3 Qualitative Research Methods

Given the limitations noted above in relation to quantitative research with refugee and asylum seeker populations, qualitative research methods may be used either as standalone methods, or in conjunction with quantitative designs, in order to provide a nuanced understanding of the research focus. Here, we outline several innovative qualitative research methods used in research with populations who may be considered “vulnerable,” including photovoice, photolanguage, and digital storytelling. Importantly, many of these research methods are based on visual information rather than text or solely spoken communication, meaning that they are a more likely to be empowering and appropriate for use with people for whom English (or the language in which the research is being conducted) is an additional language (see Crivello et al. 2009; Correa-Velez et al. 2010; Due et al. 2016 for some examples of previous uses of visual research methodologies). Below, we consider photovoice and photolanguage, digital storytelling, and the use of visual prompts in interviews.

Photovoice typically involves participants being provided with a camera and asked to take photos according to a particular theme related to the research aims or questions. Participants are then invited to discuss their images in either a focus group or interview setting (Drew et al. 2010; Liamputtong 2010; Haque and Eng 2011; see also ► Chap. 65, “Understanding Health Through a Different Lens: Photovoice Method”). Correspondingly, the photovoice method allows research participants to “lead” the direction of their responses in relation to the photographs they took, rather than following a predetermined interview schedule. In addition, the photovoice method is suitable for research with participants who may have limited English language skills (or language skills in the language of the country in which they are living). Photovoice may also be particularly relevant where the subject of the research is sensitive, as is often the case in health and well-being related research.

For example, photovoice allows participants to discuss topics of sensitivity on their own terms, which may lead to more nuanced and relevant data than direct questions (Drew et al. 2010; Haque and Eng 2011). Photovoice has been used previously in health-related research, such as research exploring understandings of well-being and cultural interpretations of health (Crivello et al. 2009).

In analyzing photovoice images, it is important to analyze the “talk” around the images, the broader context around the images, and also what is *not* photographed or discussed. For example, in a study of socioeconomically contrasting neighborhoods in South Australia, Browne-Yung et al. (2016) used the example of two photos selected by participants depicting graffiti as something they did not like about their neighborhoods. The participant from the wealthier area discussed the graffiti on a fence as unsightly and likely put there by people living *outside* the area. In the more disadvantaged area, the graffiti depicted in the photo was the “tag” of a local gang living *in* the area known to terrorize people living in the area and the image was chosen to reflect the fear that this caused for residents. Thus, the meaning ascribed to graffiti and the implications for feelings of safety and cohesion within neighborhoods was quite different in each context. A cursory analysis of the photos would have indicated that graffiti was an issue in both areas but not provided these more nuanced understandings. Likewise, a photovoice exercise with refugee children in school where they were asked to photograph places they felt safe revealed a lack of images of shared outside play spaces, suggesting that many children who were newly arrived in the school were generally relegated to the periphery of school spaces (Due and Riggs 2011).

Photolanguage involves asking participants to choose an image or images from a selected array that best represents the issue of interest (e.g., what does “home” mean to you) and to explain why they chose that image or images. It is related to photovoice methods but varies in that the images are predetermined prior to interview. This is similar to the photo elicitation method. The technique is valued by researchers and therapists alike for its “ability to challenge the viewer to thoughtful reflection” (Cooney and Burton 1986, p. 2). In addition, Fullana et al. (2014) have shown how photo elicitation methods may facilitate more inclusive participation in qualitative research. Although initially developed in 1965 as a therapeutic tool in counseling and group therapy, its merits have since been recognized in community development, pedagogical, and research contexts (Freire 2005).

Like other qualitative data-collection methods, photolanguage enables the collection of data in the form of opinions, descriptions, memories, and anecdotes. However, the use of images as a symbolic medium sets photolanguage (and photovoice) apart from some other qualitative tools. It is thought that when individuals choose an image in response to a question or probe, they are drawn to the image because it resonates with their most essential perceptions in response to that probe. This is considered to be an effective way of reducing more descriptive responses because individuals are not limited to expressing themselves through words; they can use the image to gain insight and clarity into their reaction to the question. There are some photolanguage card kits that can be used (e.g., Seamer 2007). While a predetermined set of images may constrain choices, the more abstract array can access different experiences and responses than more concrete images generally

taken in photovoice exercises. An example of photolanguage methods used in research with refugees involved asking participants about the meaning of home through presenting a selection of Seamer's (2007) images (Loehr 2016). The selection by participants of images such as a sunrise to signify the new hope associated with home ownership and a key in a lock representing the importance of security of tenure, prompted discussion of deeper issues such as the need for a fresh start and previous experiences of home not being a sanctuary from violence and fear (Loehr 2016).

Digital storytelling encompasses a short form of video media in which participants are able to narrate or provide information about various aspects of their lives using still images (photographs), video, and music (Meadows 2003; see also ► Chap. 74, "Digital Storytelling Method"). Digital storytelling has been used in a range of settings such as education and community development and more recently in a research capacity, including – in small number of cases – research with refugee populations (see, for example Lenette and Boddy 2013; Lenette et al. 2015). However, this work is in its infancy and there remain potential barriers for those who are not fluent in the dominant language of the resettlement country, with little previous research exploring digital storytelling as a viable research method when language barriers are present. Nevertheless, and as with the photovoice method, digital storytelling may also provide research participants with a powerful medium in which to share information about their lives. In one project, "Residents Voices," digital storytelling was utilized to create opportunities for social housing tenants to develop and express their own knowledge and understanding of the links between place and disadvantage. Tenants not only created a digital story through the workshops, but more importantly, they acquired the skills and knowledge to create and teach others how to create additional digital stories in the future (Rogers et al. *in press*).

4 Research with Children and Young People

Much of the existing research concerning the health and well-being of refugee or asylum seeker children has involved adults close to children (such as parents, teachers, or service providers) as research participants rather than children themselves (Due et al. 2014). However, a growing body of research has argued that children, including refugee and asylum seeker children, are able to provide important information about their own lives. As such, instead of adopting a "cognitive deficit" approach that assumes that children do not have the capacity to respond to research, such research designs use methodologies that ensure that children can participate in research on their own terms. Such research methodologies generally include a 'toolkit' of approaches (see Crivello et al. 2009; Gifford et al. 2007; Due et al. 2014; McMichael et al. 2014) which allows researchers to give children a range of options in terms of research activities, thereby increasing the likelihood that some of the activities will suit the child's preferred communication channels, as well as aiding in breaking down power relations. "Toolkit" approaches to research methodology also allows researchers to examine a number of different forms of data, enabling cross-checking of results and comparison of data, and reducing the issue of missing data

(McMichael et al. 2014). In addition, using a toolkit of approaches facilitates one of the central tenets of participatory research with children: for the researcher to enter the world of the child and, in doing so, modify research agendas to ensure that the experiences of the participants involved are reflected in the research process (O’Kane 2000). As with adult research participants, this process assists in ensuring that the research is relevant to children, particularly in relation to highly context-dependent constructs such as well-being (see also ► Chap. 115, “Researching with Children”).

In terms of the specific research methods within such a ‘toolkit’ methodology, previous research has identified the utility of photovoice designs in particular with children with refugee or migrant backgrounds (Due et al. 2014). Specifically, photovoice has been identified as a child-focused, flexible approach to research that allows children’s views to be communicated (Darbyshire et al. 2005; Newman et al. 2006; Due and Riggs 2011). In particular, photovoice has the potential to allow children to capture aspects of their lives which adults may otherwise not have access to (Young and Barrett 2001). As with adults, photovoice also allows children to highlight the issues of most importance to them, and may facilitate communication of sensitive issues relating to health and well-being, such as exposure to traumatic events.

Other visual research methods can be used as appropriate for the research aims. Examples include getting children to draw images of their happy and sad experiences (Liamputtong and Fernandes 2015), using images such as a circle and asking students to draw themselves in terms of where they felt they belong in that community (that is, towards the center of the circle if they felt they belong, and outside if they did not), asking children to draw pictures of themselves, and then to discuss aspects of the pictures that they drew that were important to them (Gifford et al. 2007; McMichael et al. 2014), or drawing ‘social network maps’ in order to consider social inclusion and belonging (Gifford et al. 2009; Block et al. 2012; Kurban and Liamputtong 2017). As noted above with adult research participants, visual or smiley-face scales can also aid the collection of quantitative data, and other novelty scales such as lolly jars may also be used (Due et al. 2014). It is also important to note that the issues noted above concerning the lack of appropriately validated health and well-being measures for refugee populations are magnified with children, with very few culturally appropriate tools for measuring health and well-being (See also ► “Visual Methods in Research with Migrant and Refugee Children and Young People,” and ► 100, “Participatory and Visual Research with Roma Youth”).

5 Data Collection

People with refugee or asylum seeker backgrounds are typically seen as a hard-to-reach research population and are frequently in very vulnerable positions (Liamputtong 2007, 2010). As such, ethical and careful data collection strategies are central to research with this population. As noted above, participatory research methods may go some way to assisting with issues of data collection, since they enable trust to be developed between the researcher and the potential participants (Pittaway and Bartolomei 2003; Kabranian-Melkonian 2015). In this section, we

consider three elements of data collection: building rapport and cross-cultural competency, sampling issues, and interpreting and translation.

5.1 Building Rapport and Cross-Cultural Competency

Building rapport and trust with the communities that the research is concerned with is a central aspect of research methodologies involving people with refugee and asylum seeker backgrounds (Pittaway and Bartolomei 2003). Such relationships enable not only access to participants, but also crucial information about cultural or ethnic norms that need to be considered in the research process. An advisory group, bilingual researcher, or research assistant from the country of origin may assist with this process, although again attention should be paid to the nuances of relationships between different ethnic or language groups in the areas relevant to the study (Lee et al. 2014; Kabranian-Melkonian 2015).

Rapport building is also of central importance to research designs, in particular where either children or unaccompanied minors are included (Vervliet et al. 2015). This process may involve (where appropriate) spending time with children prior to primary data collection, in order to ensure that the children participating in the research feel comfortable to share their experiences (Due et al. 2014; Vervleit et al. 2015). This is particularly important given that children are typically keen to please adults and thus may be likely provide socially desirable or confirmatory responses if they do not feel comfortable in a research setting (Zeinstra et al. 2009). Building rapport also assists with ensuring appropriate strategies are taken to gain ongoing assent from children, in that rapport with an individual child places a researcher in a better position from which to determine when children may be distressed, hesitant, or unsure, and therefore when to move forward in the research or stop altogether.

However, building rapport and trust can lead to challenges to researchers' perceptions of their role in participants' lives (Vervliet et al. 2015). As noted by Vervliet, researchers can become heavily involved in participants' lives (especially in the case of longitudinal research), and sometimes even build relationships with family members or support workers. In this sense, researchers may struggle with their role, leading to challenges at both a personal level and within the research itself (Due et al. 2014; Verviet et al. 2015). In this sense, research concerning health and well-being should be implemented with clear governance structures and referral pathways for research participants, such that there are clear protocols to follow where individual research participants become distressed. Some of these broader ethical issues are discussed further below.

5.2 Sampling Issues

Rapport and trust is also important so that researchers should ensure that they are able to recruit as diverse a sample as possible. As argued by Kabranian-Melkonian (2015) and Bloch (2007), much of the research conducted with refugee populations uses as its recruitment strategy one or two community or service-provider

organizations through which to access people. Recruiting using this method necessarily leads to a relatively homogenous sample (e.g., those accessing specific services or those in specific communities), and correspondingly constrains results, particularly in relation to quantitative research where the sample may not be sufficiently robust to meet standards for generalizability. Bloch (2007) notes that researchers should attempt to employ cluster sampling methods, with as many starting points as possible, in order to ensure a diverse sample which represents the broader population of interest. In addition, research that engages refugee and asylum seeker participants – such as through participatory models – may also benefit from wide snowball sampling, whereby the research participants themselves become advocates for the research and pass information on to their own networks (Hanza et al. 2016).

5.3 Interpreting and Translation

It is well established that scales, measures, and interview questions should be administered with either translation or interpreting where participants do not speak the language in which the research is being conducted (Kabranian-Melkonian 2015). Survey tools or scales should also be back-translated into their original language to ensure accurate translation, particularly for nuanced concepts or health constructs (Liamputtong 2010; Kabranian-Melkonian 2015). Nevertheless, attention should also be paid to the impact that translation may have on scale validation, and at times comparison to broader research should be done with caution.

As noted above, ensuring that interpreters' own ethnicity or culture match those of participants is also important in order to not to cross boundaries with countries and cause discomfort or distress to research participants (Liamputtong 2010; Kabranian-Melkonian 2015). This is particularly important in situations where there is conflict within a country, or where particular ethnicities are the subject of ongoing persecution. However, there can also be some confidentiality concerns about the use of interpreters from the same ethnic or cultural group particularly in small communities and around some health issues such as sexual health or domestic violence (Gartley and Due 2016). In these cases, participants may have preferred interpreters or request someone from outside their direct community but who speaks a shared language. Researchers need to be mindful of these nuances when considering approaches to interpreting (see ► Chaps. 93, "Considerations About Translation: Strategies About Frontiers," ► 95, "An Approach to Conducting Cross-Language Qualitative Research with People from Multiple Language Groups," and ► 94, "Finding Meaning: A Cross-Language Mixed-Methods Research Strategy").

6 Ethical Considerations

As highlighted above, there are diverse considerations in relation to ethics when working with people from refugee or asylum seeker backgrounds (Birman 2006; Block et al. 2012). One of the foremost of these relates to the issue of gaining

informed consent and vulnerability (Liamputtong 2010). By virtue of their previous experiences, many people with refugee backgrounds can be considered “vulnerable” in relation to their involvement in research (Ellis et al. 2007; Liamputtong 2010; Hugman et al. 2011), although the term should be used with caution (Levine 2004). This status requires consideration in research designs, particularly in relation to the ethical issue of power relations when obtaining consent to research participation. In health or mental health research, research questions can be sensitive, and researchers should be aware of issues such as the similarity of interviews or surveys to the interviews or surveys conducted as part of refugee processing, and the fact that some people may therefore not understand that participation in the research is voluntary (Ellis et al. 2007). Issues with informed consent also arrive when working with collectivist cultures who may be reluctant to decline to participate in order to benefit the broader community of which they are part (Ellis et al. 2007), and from cultural norms concerning who gives consent for others (including gender relations and the status of the elderly or children).

Many people with refugee or asylum seeker backgrounds may be hesitant to sign consent forms due to previous negative experiences with signing documents or cultural norms concerning placing a signature (Liamputtong 2010; Kabranian-Melkonian 2015). As such, it may be more appropriate to gain recorded verbal consent prior to the start of an interview, or to state that consent is assumed if participants agree to complete a survey. Critically, it is important to ensure that all project information is translated into a language in which potential participants can understand, or that there is scope in a project to have a neutral person explain the project to participants, if appropriate. Moreover, the process of informed consent should be seen as an iterative, rather than once off, process, such that participants who are involved in multiple stages of data collection or long data collection process are provided with an opportunity to provide ongoing assent to the project, and withdraw if they wish (Mackenzie et al. 2007). In this sense, then, the process of gaining consent should not be seen as a once-off, single event, but rather an ongoing situation of negotiation and shared understanding about the research process (Mackenzie et al. 2007). Recording of interviews can also be challenging for participants who may be concerned about such recordings being used against them, for example, in determining the outcome of their claim for asylum. Again, for the researcher, this is a delicate balance of being able to report on people’s experiences in their own words and the need to be responsive to people’s apprehension about recorded interviews.

Relatedly regarding assurances of confidentiality and/or anonymity attention should be paid to the possibility of identifying participants in new and emerging communities. This is particularly important in qualitative research which might involve the publication of individual extracts or participant information which is not aggregated. In this situation, particular combinations of demographic details (age, gender, country of origin, ethnicity, family size, religion, number of years in a country) may be combined in such a way that individuals from new or emerging communities can be identified. In health research specifically, such identification may lead to negative consequences for research participants. Here, then, researchers

should balance the need to provide sufficient details to ensure the research can be assessed as reliable or replicable, with the imperative to protect research participants from harm (Liamputtong 2007, 2010).

Particular ethical issues arise in relation to working with children with refugee backgrounds, particularly in relation to obtaining informed consent (Due et al. 2014). Clearly, standard practice for research is the requirement to gain informed consent from parents or carers for child participants. However, the fact remains that obtaining consent in this manner does not take into account the child's own willingness to work with the researchers or participate in the study, and this is particularly the case given cultural differences and considerations in relation to obtaining consent from adults or assent from children (for example, determinations of power based on premigration experiences, see Morrow 2008). Correspondingly, where possible, ongoing "assent" should be gained from child participants, such that the project is explained to them and they have a choice regarding their participation that is on their own terms to the extent that this is possible. For example, children should not be pressed to answer questions or participate in activities that they do not wish to complete. While verbal assent should always be gained from children, it should also be noted that this process may not always reflect an autonomous agreement to participate in an activity, particularly where research is conducted in an "adult" environment such as a school (Punch 2002). As such, a similar iterative process to that noted above should be used, whereby children provide assent at every stage of the research (Block et al. 2012).

Another issue pertaining to ethics lies in relation to considering the well-being of research participants themselves (Jacobsen and Landau 2003). Researchers should consider the potential impact of the research on the possibility of retraumatization, and there should be a comprehensive plan to refer participants to services if required. Correspondingly, research with refugee participants should pay particular attention to the requirement to "do no harm" (Hugman et al. 2011). On the other hand, research has also found that participation in research can be empowering for participants (Newman and Kaloupek 2004; Ellis et al. 2007) and that research which involves interventions may be of direct benefit to communities (Ellis et al. 2007). As such, researchers should weigh the risks and benefits of their research, and ensure that the benefits outweigh the risks before they proceed (Ellis et al. 2007).

It is also important to note that some researchers have highlighted that erring too far on the side of caution in relation to "protecting" refugees from research can be paternalistic and may lead to inequalities relating to the lack of refugee voices in research (Kilpatrick 2004). This situation is in itself unethical and may lead to negative outcomes for refugees and asylum seekers, particularly if there is a lack of health and well-being research from which to develop appropriate interventions or assistance (Birman 2006). Correspondingly, researchers should ensure that where possible refugee and asylum seeker voices *are* heard in research, rather than reliance on others (e.g., service providers, healthcare professionals). In this sense, then, ethical research with refugees and asylum seekers can be seen to involve a fine balance between rigor, advocacy, benefit, and inclusion in the research process (see also ► Chap. 106, "Ethics and Research with Indigenous Peoples").

7 Advocacy

While most researchers agree that close community collaboration is a central aspect of research design with refugees and asylum seekers, it is also worth noting that one of the main tensions in research with refugees on any research topic is that of the role of advocacy in research. Some researchers (e.g., Jacobsen and Landau 2003) have suggested that much research with refugees is politically charged and does not meet standards for rigorous research that can be seen as reliable or valid. This lack of rigor is noted primarily due to *a priori* assumptions on the part of the researchers about what the research outcomes will be, as a result of a desire to enact social or political changes on the basis of the results. On the other hand, other researchers (e.g., Mackenzie et al. 2007) have suggested that ethical research with refugees *should* lead to better outcomes for those affected by the research, and that given the frequently desperate situation of many refugees, academics should also stand in solidarity with research participants through advocacy-type roles. Mackenzie et al. (2007, p. 316) state:

When a human being is in need and the researcher is in a position to respond to that need, non-intervention in the name of “objective” research is unethical. Further, it could be argued that if researchers are in a position to assist refugees to advocate on their own behalf . . . that it is morally incumbent on them to do so.

Indeed, in many contexts around the world, academics have taken an advocacy stance as a result of their research, resulting in letters to politicians and the media, and petitions for issues such as asylum seeker policy and refugee education or access to healthcare (Hartley et al. 2013). Correspondingly, we argue in this chapter that research with refugees should be balanced between meeting academic standards of rigor and objectivity, while also leaving room for advocacy (Block et al. 2012). This is particularly important for research concerning refugee mental and physical health, and the social determinants of health, where the findings of a research project could be directly relevant to policy and practice. In such situations it is arguably unethical for researchers to *not* use the outcomes of their research to advocate for change.

8 Conclusion and Future Directions

As noted above, it is critical that any health research that seeks to document the lives of people with refugee and asylum seeker backgrounds also includes their voices, and takes into account specific cultural knowledges and understandings concerning health and well-being. In this regard, researchers need to balance several key considerations in design research protocols concerning refugee health. This includes particularly the need to consider the use of culturally appropriate research methods while also ensuring that research processes and tools are valid and reliable. In addition, it is important to think broadly about health and wellbeing—such as through

a SDoH approach – to allow for a nuanced examination of the sociopolitical circumstances in which refugees live or have lived.

Clearly, refugee and asylum seeker health is a crucial area, and one in need of more research that can inform policy and practice as the numbers of refugees worldwide continues to increase. However, in addition to applied research concerning health and well-being, there is also a need for researchers to develop methodologies and research tools to ensure that research in this area can be rigorous and can include appropriately validated tools through which to draw conclusions. In particular, there is a critical need for physical and mental health scales that are validated cross-culturally, specific to the refugee population, and validated for diverse language groups. This is particularly the case in areas such as child trauma (Ehnholt and Yule 2006). Furthermore, there is a need for an evidence-base to consider methodologies, and the ways in which rigor can be balanced with diverse methods that include the voices of refugees, and that incorporate community understandings into research practices.

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Ethical Issues in Cultural Research on Human Development

108

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Contents

1	Introduction	1892
2	Cultural Broadening of Operational Definitions	1893
3	Cultural Adequacy of Procedures and Modes of Data Collection	1895
3.1	Informed Consent	1895
3.2	Privacy	1897
3.3	Minimizing Harm	1898
4	Ethical Considerations in the Interpretation and Reporting of Data	1900
5	Conclusion and Future Directions	1902
	References	1902

Abstract

This chapter addresses ethical issues in cultural research on human development. We argue for the importance of attending to culture in all phases of the research process and highlight ways that promoting the ethical sensitivity of cultural research enhances its validity and explanatory force. The first portion of the chapter focuses on early phases of the research process. We underscore the need to operationalize constructs in culturally valid ways and identify challenges that arise when objectively comparable procedures involve culturally variable meanings. The next section focuses on ethical issues in sampling, including the importance of tapping understudied populations and respecting local cultural norms in securing informed consent. We next address ethical aspects of study design and data collection, pointing out ways that harm, coercion and invasion of

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privacy that may result from inadequate attention to cultural meanings and practices. Lastly, we discuss the impact of drawing unsound or stereotypical conclusions about culture and human development, while discussing the insights cross-cultural research has to offer in terms of broadening psychological constructs, contributing to basic psychological theory, and making the discipline less culturally parochial. We conclude by outlining ways in which culturally sensitive research can enhance both ethics and research quality.

Keywords

Ethics · Confidentiality · Informed consent · Privacy · Harm · Attachment · Parenting · Motivation · Culture

1 Introduction

Research ethics in the field of psychology mandate that psychologists conduct their research in accord with ethical principles. As in other health and social science research, psychologists must be concerned not only with protecting the human rights of research participants, including their rights to privacy and to protection from harm, but also with insuring the welfare of research participants and of the larger community affected by psychological research findings. As we will argue, to meet these goals, psychologists must adopt practices that take into account the cultural beliefs, values, and practices of the populations involved in and affected by their work (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)).

As an illustration of the ethical challenges that arise in taking cultural considerations into account in research on human development, we begin with an example of an ethical dilemma that we encountered while planning a study among fourth-grade elementary school children in the USA. We had designed the study to assess the relationship between young children’s empathy and their interactions with pets. Our methods included: (a) basic demographic questions; (b) a short questionnaire that assessed reactions to short stories about hypothetical children; and (c) emotion recognition probes. We submitted a research proposal describing our research materials to the Institutional Review Board (IRB) at our university and received the following feedback:

I would ask that the (demographic) question ‘Are you a boy or a girl?’ be changed to ‘Do you see yourself as a boy, a girl, neither of these, or something else?’ Likewise in the questionnaire the proper names of the (hypothetical) children in the story can replace he/she. These changes are easy to accomplish yet showcase the ways in which our university is inclusive and does not promote the binary depictions of gender and the stereotypes associated with them.

Upon first glance, this feedback may seem reasonable, as the IRB was urging us to be more inclusive of sexual and gender minority populations. However, the feedback was ethnocentric in reflecting the value system of our liberal university’s culture but not the more conservative value system of the suburban community

in which we would be carrying out the project. Although eliminating the pronouns in our vignettes would be nonproblematic, the rephrasing of the demographic question advocated by the IRB would be experienced as foreign and possibly intrusive by the research participants in that it did not reflect the local cultural context, but rather the culture of the IRB members with their progressive agenda. By rephrasing the demographic question in the way suggested, we would have introduced an unfamiliar and potentially uncomfortable way of conceptualizing gender to the children without having obtained prior consent from their parents to do this – consent that it is likely the parents would not have given. Moreover, we would be undermining the validity of our study, as children might have been confused about the meaning of this modified gender probe.

The response that we made to the IRB was improvised in that ethical guidelines of IRB committees do not typically address how to make accommodations for this type of case. We were faced with a situation in which two ethical challenges (inclusion vs. harm) were in direct conflict. However, our IRB had failed even to recognize this conflict much less to adjudicate which ethical issue should take precedence over the other. Rather than complying with what we judged to be an ethically problematic IRB ruling, we counter-proposed that our demographic question be modified to an open-ended probe about gender that would be completed by the child's teacher, rather than either by the child or their parents. This allowed us to be inclusive, while at the same time avoiding harming the children and their parents, and retaining the integrity of the investigation.

In this chapter, we present an overview of ethical issues that arise in cultural research on human development in all phases of the research process. Considering early phases of the research process, we begin by underscoring the need to operationalize constructs in culturally valid ways and to identify challenges that arise when objectively comparable procedures reflect culturally parochial meanings. We next address ethical issues in data collection, including the importance of sampling understudied populations and of respecting local cultural norms in securing informed consent, as well ethical aspects of study design, including ways to avoid harm, coercion and invasion of privacy that may result from inadequate attention to cultural meanings and practices. Lastly, we discuss the impact of drawing unsound or stereotypical conclusions about culture and human development, while discussing insights that cultural research has to offer in terms of broadening psychological constructs, contributing to basic psychological theory, and making the discipline less culturally parochial.

2 Cultural Broadening of Operational Definitions

To achieve fairness in formulating initial research questions, it is important to attend to cultural variation in the meaning of the constructs under consideration and in their operational definitions. Research may fail to capture the perspective of certain cultural groups as the constructs under consideration may embody culturally bound meanings and assumptions. This type of concern may be illustrated in

research on parental control. Developmental psychologists make a distinction between authoritative and authoritarian parenting styles (Baumrind 1966, 1996; Darling and Steinberg 1993). Whereas authoritative parenting is based on behavioral control, involving active guidance and direction of the child's behavior, authoritarian parenting is based on psychological control, involving the use of strategies such as manipulation, guilt induction, and coercion (Baumrind 1966, 1996; Conger et al. 1992; Coplan et al. 2002). It is assumed that positive affective experiences and beneficial adaptive outcomes arise from authoritative parenting styles whereas affectively harsh affective experiences and maladaptive outcomes arise from authoritarian parenting styles (Baumrind 1966, 1996; Conger et al. 1992; Coplan et al. 2002; Baumrind et al. 2010).

Among European American samples, researchers have observed that authoritative parenting styles are associated with closeness in parent-child relationships and higher academic achievement, whereas authoritarian parenting styles are associated with affectively distant parent-child relationships and lower academic achievement (Barber et al. 1994; Chao 2001; Jackson-Newsom et al. 2008). Additionally, research conducted among a large sample drawn from the USA found that adults who remembered the parenting style of their parents as being authoritative reported less depression and greater well-being than those who remembered it as being authoritarian (Rothrauff et al. 2009).

On the widely used standardized scale of parenting, the Child Report of Parenting Behavior Inventory (CRPBI, Schaefer 1965) the following item is included to tap authoritarian parenting: "[my mother or primary care giver] says if I really cared for her, I would not do things that cause her to worry." Whereas most youth associate feelings of being controlled by their parents with this scale item, African American children associate this scale item and similar authoritarian scale items with feelings of being cared for and loved (Mason et al. 2004). Thus, when African American populations are classified as authoritarian on the basis of their CRPBI responses, it is unclear whether this classification is actually reflective of their maintaining an authoritarian parenting orientation, given the positive affective meanings African-Americans tend to associate with parental control. Likewise, research conducted among Asian-American populations indicates that controlling forms of parenting are interpreted as reflecting parental warmth rather than parental harshness (Chao 1994, 1995, 2001) and that authoritarian parenting is associated with positive academic performance (Dornbusch et al. 1987). In sum, the affective significance and behavioral correlates of authoritarian parenting as measured by indices such as the CRPBI are culturally variable and thus it cannot be assumed that the constructs measured by a scale such as the CRPBI have the same meaning in different cultural groups. In this type of case in which the constructs under consideration on a standardized scale have culturally variable meanings, a researcher should not simply adopt the scale in its original form with cultural populations on which it has not been validated. Rather, researchers must adapt the scale measure in ways that make it more culturally appropriate for the particular cultural community under consideration or design their own measures that have greater cultural validity.

Cultural sensitivity in the operationalization of psychological constructs also allows researchers to avoid potential harm caused by inappropriately applying research findings in real world settings. For example, a parental education program that is encouraging parents to adopt an authoritative parenting style, and that is discouraging their reliance on more controlling styles of parenting, may have the effect of leading children to feel rejected or unloved if the affective meanings of the parenting styles in their cultural community are different from that assumed in the concept of authoritarian parenting. Efforts made to integrate culture-specific concerns into parenting interventions for Latino communities in the USA have been well received by participating parents (Parra-Cardona et al. 2016) and highlight the ethical importance of operationalizing constructs in a culturally sensitive manner.

Additionally, parents may feel that their personal parenting practices are being disparaged if psychologists portray the parenting style that is normative in their community as flawed because it does not match that of the middle class European American cultural communities on which the constructs of authoritative versus authoritarian parenting styles are based. Taking cultural considerations into account during the early phase of construct operationalization is integral then not only to ensure the validity of research but also to protect research participants and consumers of psychological research findings.

3 Cultural Adequacy of Procedures and Modes of Data Collection

Researchers must be culturally aware not only in the formation of their research ideas but also during the process of data collection. Cultural challenges that arise in the process of data collection include being attentive to the cultural context while obtaining informed consent, taking cultural considerations into account in ensuring the privacy of participants, as well as protecting participants from culturally variable sources of harm (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)).

3.1 Informed Consent

Informed consent is a process for obtaining permission from prospective research participants to be part of a research study while providing them with information about the nature of the study and the potential benefits or harm associated with participating in it. As children lack the legal right to refuse to participate in research and in many cases the cognitive maturity to fully understand research procedures, efforts must be made to fully explain the nature of any benefits and risks associated with research to parents and guardians of the children. Moreover, in cases in which children are able to provide verbal and/or written consent, researchers must make efforts to obtain written consent from minors through assent procedures that are written in simplified child-centered ways.

Ensuring a child's consent and full comprehension of the study procedures is a challenging but important step in conducting research among children from diverse cultural groups. For example, in a series of studies conducted in Canada, elementary school children were able to accurately describe the nature and purpose of the study but significantly underestimated the potential risks associated with participating it, such as feelings of being embarrassed or upset by their performance, or being bored by the length of a particular questionnaire or study (Abramovitch et al. 1995). Children may also overestimate the potential benefits of participation or expect benefits which may be difficult to predict based on the nature of the research being conducted (Miller and Feudtner 2016). These types of concerns may be even more pronounced in the case of populations that have limited exposure to the norms of Western experimentation. In such cases, individuals may not anticipate that psychological research is commonly impersonal and hence they may react negatively to research contexts on the grounds of its impersonality. For example, AIDS research conducted among African Americans showed that participants viewed many standardized questions as disrespectful of their feelings and experiences (Stevenson et al. 1993).

Cultural variations in conceptions of authority also need to be taken into account when obtaining informed consent. For example, among European Americans it is common practice to obtain consent from the parent or legal guardian of the child, who is bestowed the right to accept or decline their child's participation in a research study. However, in the case of American Indian or Alaskan Native tribes, it may be considered essential to consult with and obtain prior approval from the tribal leaders about whether, how, and when investigators should approach children and their families within the tribe (Beauvais and Trimble 1992; Norton and Manson 1996). Likewise, in the case of certain Asian cultural groups, consent may be viewed as a family right, and thus, it is expected to be secured from parents, guardians, and grandparents even in cases in which an adolescent child is legally permitted to give consent (Tai and Lin 2001).

In enhancing the sensitivity of their research in diverse cultural contexts, researchers need to give additional attention to ensuring that consent is voluntary. Although consent forms include a stipulation that participants are free to withdraw at any time without penalty, in research with children, especially across different cultural contexts, this freedom might not be salient. For example, Abramovitch et al. (1995) have demonstrated that children are less likely to withdraw from a study if the experimenter does not voluntarily reiterate that he/she will not be upset with the child for stopping participation. This tendency not to treat research participation as voluntary may be further exacerbated in cultural communities in which individuals are prone to defer to authority, as members of such cultural communities may be even less familiar with psychological research norms than their European American counterparts. When concerns do arise during the process of obtaining consent, not all participants may be equally willing to ask questions of the researcher. Specifically, participants of lower socioeconomic status, who tend to ask fewer questions than those of higher SES during the informed consent process, may miss

an opportunity to obtain all of the information required to make a truly informed decision (Rajaramn et al. 2011).

Finally, researchers also need to take special care to ensure that compensation provided for research participation is fair, noncoercive, and afforded the same meaning in different cultural communities. For example, if participation by the family is given with the sole aim of contributing to scientific research (i.e., an altruistic act), offering compensation could be construed as offensive or infringing on family values. Moreover, if families accept compensation for their participation, efforts must be made to ensure the equality of compensation in different cultural settings, such that one cultural group does not get over-compensated or under-compensated due to different spending power associated with their currency. Additionally, the compensation offered should not be so great as to be experienced by individuals as compelling their participation but not so low that participants feel exploited.

3.2 Privacy

Privacy in the research context entails: (a) physical privacy, i.e., providing spatial seclusion; (b) informational privacy, i.e., ensuring confidentiality and protection of data; and (c) decisional privacy, i.e., allowing participants to make decisions for themselves, especially decisions concerning sex, religion, and/or reproduction (Allen 1999). As explained below, in all of these instances, special concern must be taken into account to achieve cultural sensitivity.

Contrasting cultural norms concerning physical space and openness may affect the meaning and desirability of physical and informational privacy in the conduct of research. For example, a recent public health interview study undertaken in Sri Lanka, which compared the outlooks of Buddhist, Western, and Ayurvedic healers, demonstrated that respondents were “uncomfortable” with participating in interviews in hidden spaces, such as closed offices – a behavior that was normative among Western participants. When these same participants were moved to public patio spaces, they participated in research with less hesitation and unease. Furthermore, in the public health interviews, the research participants were also found to be more comfortable coming to the interviews accompanied by their significant others, parents, or close friends, and felt safer disclosing information in the presence of these significant others (Monshi and Zieglmayer 2004). Thus, in seeking to protect the privacy of information collected, researchers should be mindful about different cultural outlooks concerning the meaning and practice of privacy.

Variation in cultural values underlying decisional privacy must also be taken into account when determining who has the right to obtain information and make decisions about the participant, especially in the case of children. One central issue that arises is the weight to be given to the rights of adolescents to control their own behavior. Since older adolescents have the same cognitive capacity as their adult

counterparts as well as engage in adult-like behaviors, such as driving and drinking alcohol, arguments that hold true for younger children no longer constitute clear grounds for the parents' rights to make decision on behalf of their adolescent offspring. In resolving such conflicts, however, attention should be given to cultural norms about parental involvement.

For example, in research conducted with US samples, researchers have concluded that in the case of major health decisions when a parents and adolescent disagree on the right of the youth to control his/ her behavior, priority should be given to the rights of the adolescent (Brooks-Gunn and Rotheram-Borus 1994). Researchers commonly argue that a youth should have autonomy over his/her own behavior and that the involvement of parents may preclude the adolescent from gaining access to the health care she needs. However, in many non-Western cultural communities (or even in the case of ethnic subgroups within the USA), families play a more central role in planning the adolescent's life than among European Americans. In such cultural communities, adolescents may themselves afford greater legitimacy to parental involvement than in middle class European American cultural contexts and expect their parents to be more involved in significant everyday life decisions. Thus, in such instances, it could potentially be experienced as disrespectful or intrusive to the parent-child relationship to bypass the parent by withholding information from them about their adolescent's research participation, especially in cultural communities in which the adolescents themselves value such parental input in the research process (Casas and Thompson 1991; Fisher 2002).

3.3 Minimizing Harm

Minimizing harm in the research context entails balancing the risks that human subjects may encounter by participating in scientific research with the benefits to scientific insight. It is not surprising then that the subjective experience of risk is culturally variable. Yet, historically, most experimental procedures have been created taking into account the cultural norms and expectations of European American families. Although most experimental procedures induce some level of stress, the stress is generally judged to be temporary and to be no greater than general stress involved in daily life. However, when research procedures violate everyday socialization practices of the cultural communities of research participants, they may entail greater potential for harm or discomfort than everyday stress.

For example, the Strange Situation procedure designed to assess attachment behavior created by Ainsworth (1963) was intended to induce mid-level stress in children and their primary caregivers by subjecting them to periods of separation and communion. In this procedure the infant, for a brief period lasting several minutes, interacts with an unfamiliar adult in the absence of his/her primary caregiver and is thus at times left alone. Although this procedure invariably

induces some distress in the child, this distress is deemed to be temporary and used to gain insight into the child's attachment style. This procedure is routinely approved by the Human Subjects Committees (IRB) as Ainsworth has demonstrated that the procedure is congruent with commonly experienced American practices and thus entails an acceptable level of risk. However, Takahashi (1982) notes that this type of behavior rarely occurs in Japan, as Japanese mothers rarely leave their children alone, even in the presence of other family members such as grandparents, aunts, and uncles. When the Strange Situation was administered to a sample of Japanese infants (Takahashi 1986; Takahashi and Hatano 2009), Japanese infants were interpreted as being predominantly anxiously attached to their caregivers. However, it is unclear whether the anxiety displayed by the infants was in response to the stress of the procedure or reflective of their attachment style.

To give another example, the Still Face paradigm (Tronick et al. 1978) is another experimental procedure employed with infants that is discordant with parenting practices and beliefs in cultural communities outside the dominant, white middle class model that is taken to be the default in developmental science research. In this procedure, mothers are instructed to interact in face to face play with their infants for 2 min, after which they are asked to maintain a still face for 2 min followed by another interactive face to face play for another 2 min. These interactions are later coded for the baby's emotional self-regulation as well as the mother's capacity to reengage the infant (Tronick and Cohn 1989).

Although most infants are expected to be distressed by the still face period involving the extreme nonresponsiveness, marked cultural differences occur in the process through which self-regulation is achieved (Meléndez 2005). Whereas !Kung San hunter-gatherers of Botswana tend to respond to babies' cries within 10 s, Western mothers tend to refrain from responding to their infants' cries as much as 40% of the time (Barr 1999) and may not even identify a cry as requiring a response unless it has persisted for 10 min (Small 1998). Moreover, in many cultures of Africa and Southeast Asia, infants tend to self-regulate before making a full blown cry (Papousek 2000). Given the contrasting expectations of parental responsiveness to infant distress, it is probable that the Still Face Paradigm entails more stress and thus more harm and discomfort in certain cultural communities than in others. Thus, in the case of the Strange Situation, Still Face Paradigm, and other experimental procedures that involve culturally variable levels of stress, researchers need to make significant modifications to the consent agreements, if not also to the procedures themselves, in order to adapt them for use in different cultural contexts. Although it may be reasonable to describe such procedures as involving a minimal level of harm to European American families, this type of assurance may not apply in cultural communities in which parenting practices differ markedly. It is also important to modify the procedures themselves to minimize the harm caused by their use in diverse cultural communities, as well as to substitute procedures that have greater cross-cultural validity.

4 Ethical Considerations in the Interpretation and Reporting of Data

Ethical considerations related to culture extend beyond study design and data collection to the final stages of interpreting and communicating the study results. Drawing conclusions that avoid unwarranted generalizations and provide accurate representations of diverse populations is not just a matter of producing valid scientific research but also an ethical imperative. This ethical imperative includes avoiding drawing overly broad conclusions about populations based on limited samples as well as avoiding biased and stereotypical conceptualizations of the groups being studied. Both of these can be seen as matters of ethics in that they involve fairness, in terms of the inclusivity of diverse populations and their unbiased portrayal.

Psychological research draws a disproportionate amount of data from a small segment of the world's population. This heavily sampled demography, consisting of predominantly educated Western individuals living in wealthy, democratic, industrialized countries forms the basis for many universalistic claims about human behavior (Henrich et al. 2010). An analysis conducted by Arnett of six major APA journals published between 2003 and 2007 found that only 3% of the samples were from Asia, 1% from Latin America, and 1% from either Africa or the Middle East; the remaining 95% of the samples were drawn from the USA, other English-speaking countries, or Europe (Arnett 2008). Formulating generalized claims based upon such a limited sample is made even more problematic by the fact that the individuals comprising this narrow slice of humanity are in many respects a poor representation of the rest of the world, as shown by comparative studies investigating cognition and behavior ranging from visual perception to theories of folkbiology (Henrich et al. 2010).

In research on human development, relying upon a narrow, biased sample base reflects a lack of appreciation for the role of the sociocultural environment in shaping human development. Different contexts afford access to experiences that may have significant effects on development. Studying children in varying cultural contexts provides a necessary check on assumptions that psychological development among children raised in Western, educated, wealthy, white families is the universal default. One example of this can be seen in children's folk theories of biology (Henrich et al. 2010). Much research conducted on children's folk-biological reasoning has taken place in urban settings in which children have limited experience interacting with the natural world (Henrich et al. 2010). Thus, among these urban samples, children's biological reasoning before age 7 tends to be anthropocentric, relying strongly on humans in making inferences about other living things (Carey 1985). This would be expected given the human-centered world in which urban children grow up as well as the limited exposure the children have to various living things present in the natural world. Children raised in rural environments, who have more frequent and rich interactions with the natural world, however, did not display this tendency to employ anthropocentric folkbiological reasoning (Ross et al. 2003).

In addition to giving limited attention to cultural diversity in child development, research on early child development is lacking in socioeconomic diversity, with research underrepresenting children from disadvantaged families (Fernald 2010). Developmental research typically relies disproportionately on narrow samples comprised of parents with the financial means and motivation to go out of their way to participate in studies. This is especially problematic because of the variability in access to certain types of cognitive stimulation for children of differing levels of SES, which may affect aspects of cognitive development (Fernald 2010).

It could be argued that the sampling bias in psychology is in itself an ethical violation of fairness in its failure to create a science of mind that is representative of the full spectrum of human thought and behavior. Collecting data across diverse cultural and socioeconomic contexts is an important first step in addressing this problem and making research on human development more inclusive. However, in doing so, researchers must pay adequate attention to the manner in which they represent the beliefs and attitudes of the communities involved. Specifically, great care must be taken to avoid an overly homogenized and stereotypical portrayal of the population of interest. Just as conducting research among diverse cultural communities requires careful consideration of potential variability in the interpretation and impact of study procedures, researchers choosing to undertake the important task of conducting cross-cultural research must also take seriously the challenge of adequately representing the sampled population.

Cross-cultural research conducted among East Asian populations is an example of an attempt at cultural inclusivity that often falls prey to such an overly homogenized approach to culture. It does this through making unjustifiably global claims about “Asian culture” or even “Eastern culture” based on samples composed of individuals coming from a diverse set of countries (e.g., Japan, China, Korea) with distinct sociohistorical backgrounds and strikingly different cultural traditions (e.g., Nisbett 2003). Conceptualizing culture in this way overlooks not only nationality but also variability in other factors such as religion, which lead to greater within-group diversity in attitudes and behavior than is implied by global cultural categories (Fisher 2002).

Conceptualizing cultural communities in overly homogenized terms is problematic in its failure to accurately represent the population of interest, and it is also prone to stereotypical characterizations of such groups. Data may be interpreted or summarized based on preconceived, stereotypical notions of large, heterogeneous groups. This may be exacerbated by an over-reliance in the field on attempts to measure large-scale cultural orientations, such as individualism-collectivism (Hofstede 1980) and independent-interdependent self-construal (Markus and Kityama 1991), accompanied by attempts to plot entire nations along these dimensions (e.g., Hofstede 1984). Categorizing cultural groups in this manner sacrifices a more nuanced, sensitive approach to culture by applying broad labels based solely on endorsement of decontextualized individual difference scale items.

5 Conclusion and Future Directions

In order to conduct ethically sound research on human development, culture is an issue that should be seriously addressed at every stage of the research process. Taking culture into account goes beyond considering the adequacy of procedures across cultural contexts, though this is surely of great importance. Culture should also factor into the initial theoretical constructs, which frame the study design, and carry through to the interpretation of the results, in addition to guiding all of the steps in-between. A failure to consider culture during any of these stages raises the possibility of an ethical breach and has the potential to diminish the quality of the work.

While lack of attention to culture presents a serious problem with ethical implications, psychologists who choose to conduct cross-cultural research must also give serious thought to negotiating the complexities inherent in applying ethical guidelines across diverse contexts. The necessity of being sensitive to how codes of ethics might be interpreted and experienced by local communities makes taking a cultural perspective on research ethics a challenging endeavor, but it is also one that is indispensable to making valid, meaningful contributions to the study of human development.

With globalization comes an increase in opportunities for cross-cultural collaborative research, which has the potential to paint a more representative picture of human development. Such collaborations also allow for meaningful and productive cooperation between researchers from different cultural backgrounds with regard to how best to implement ethical guidelines in diverse settings. This ease with which these research collaborations can span the globe thus provides an ideal atmosphere for not only conducting high-quality cross-cultural research on human development but for considering multiple cultural perspectives on the most ethical way to do so.

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Section IV

Sensitive Research Methodology and Approach: Researching with Particular Groups in Health Social Sciences



Sensitive Research Methodology and Approach: An Introduction

109

Pranee Liamputtong

Contents

1	Introduction	1907
2	About the Section	1910
	References	1915

Keywords

Sensitive research · Vulnerable people · Marginalized people · Hard-to-reach people · Hidden populations · Sensitive topics · Elites · Experts

1 Introduction

The goal of research is “that of discerning and uncovering the actual facts of [people]’ lives and experience, facts that have been hidden, inaccessible, suppressed, distorted, misunderstood, ignored” (Bergen 1993; Bergen 1996, p. 200).

This section of the Handbook covers sensitive research methods and approaches when researching with particular groups of individuals and groups. The section includes chapters which are related to those who are referred to as vulnerable, marginalized, hard-to-reach people, hidden populations, as well as the elites and experts.

Within the present climate of our fractured world, it is inevitable that health and social science researchers will engage with the vulnerable, disadvantaged, and marginalized groups as it is likely that these population groups will be confronted with more problems with their health and well-being. Despite this, only a few books document and provide advice about how to go about performing research with

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1907

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vulnerable people (see Renzetti and Lee 1993; Liamputtong 2007; Pitts and Smith 2007; Aldridge 2015; van Liempt and Bilger 2009). This lack of discussions, as Melrose (2002, p. 338) points out, may leave researchers “feeling methodologically vulnerable, verging on the distressingly incapable, because of emotional and anxiety challenges, and thus ill equipped to deal with some of the issues that may arise in this context.” In this section of the Handbook, I bring together a number of chapters that discuss some important issues for the conduct of research within the vulnerable groups of people in health and social sciences.

The “vulnerability” is a socially constructed concept (Liamputtong 2007; ten Have 2016). Thus, vulnerable individuals have been referred to in multiple ways (Liamputtong 2007; Bracken-Roche et al. 2017). The word “vulnerable people” implies “the disadvantaged sub-segment of the community requiring utmost care, specific ancillary considerations and augmented protections in research” (Shivayogi 2013, p. 53). The vulnerable, according to Quest and Marco (2001, p. 1297), are people with “social vulnerability.” They suggest that some population groups, including children, unemployed, homeless, drug-addicted people, sex workers, and ethnic and religious minority groups, face particular social vulnerability. When involving them in their research, these groups of people need special care from the researchers. Stone (2003, p. 149) refers to the “vulnerable” as individuals who are “likely to be susceptible to coercive or undue influence.” To Stone (2003), the “vulnerable” includes children, pregnant women, mentally disabled persons, or those who are “economically or educationally disadvantaged.” Punch (2002, p. 323) suggests that children are marginalized in an adult-dominated society, and as such they “experience unequal power relations with adults and much in their lives.” In this sense, children are particularly vulnerable in society, particularly when it involves abusive behavior on the part of adults in their lives (see also Melrose 2002). Some groups may be vulnerable due to their so-called legal status. Some immigrants in the United States, for example, are undocumented immigrants (see Birman 2005). Due to their illegal status, they are denied access to health and social services. Most of these groups live in poverty, and most are employed in seasonal cropping industries which are prone to poor health and bad living situations.

Vulnerable individuals have also been referred to as “marginalized” people. Marginalized people, according to O’Donnell et al. (2016, p. 198), are those “populations outside of ‘mainstream society.’” They are “highly vulnerable populations” who are “systemically excluded from national or international policy making forums.” Marginalized individuals and groups include the homeless, drug users, sex workers, refugees, and ethnic minorities such as Roma and Irish Travellers. Often, they “experience severe health inequities” and have “poorer health status than the general population” (see also ► Chap. 110, ““With Us and About Us”: Participatory Methods in Research with “Vulnerable” or Marginalized Groups”).

Whatever definition we may use to best represent the “vulnerable” or the “marginalized,” it is clear that extreme sensitivity is needed in the conduct of research with these groups (ten Have 2016). Johnson and Clarke (2003, p. 422) contend that

in conducting sensitive research, “the process of gathering such information necessarily involves direct contact with vulnerable people, with whom sensitive and difficult topics are often raised and sometimes raised within difficult contexts.” Therefore, undertaking research with vulnerable groups can present numerous serious difficulties for the researcher as well as the researched (see Melrose 2002; Liamputtong 2007, 2013; Dickson-Swift et al. 2008; Menih 2013; Shivayogi 2013; Aldridge 2012, 2015; Couch et al. 2014; McCauley 2015; Quinn 2015; Bracken-Roche et al. 2016, 2017; Wrigley and Dawson 2016; Medeiros 2017). It also raises many ethical concerns (see Menih 2013; Solomon 2013; Schrems 2014; ten Have 2015, 2016). Despite potential difficulties, the task of undertaking research with the vulnerable and marginalized participants can also present researchers with unique opportunities. Many chapters in this section illustrate these.

Closely linked with vulnerable and marginalized people is the concept of “sensitive research” (Liamputtong 2007). Social researchers increasingly undertake research on topics which are “sensitive” as they are concerned with behavior that is “intimate, discreditable, or incriminating” (Renzetti and Lee 1993, p. ix; see also McCosker et al. 2001; Lee and Lee 2012). Sensitive research, Dickson-Swift (2005, p. 11) suggests, “has the potential to impact on all of the people who are involved in it.” Similarly, according to Lee (1993, p. 4), sensitive research poses several threats to the people: intrusive threat, a threat of sanction, and political threat. Research that intrudes into private lives of the research participants will create stressful experiences as well as pose intrusive threats to them. Barnard (2005, p. 2) refers sensitive research to those projects dealing with the “socially-charged and contentious areas of human behaviour” such as the impact of parental drug problems on the well-being of their children, or underage sex work (see ► Chap. 121, “Researching Underage Sex work: Dynamic Risk, Responding Sensitive, and Protecting Participants and Researchers”). Sensitive topics would be “often the ‘difficult’ topics – trauma, abuse, death, illness, health problems, violence, crime – that spawn reflection on the role of emotions in research” (Campbell 2002, p. 33).

Renzetti and Lee (1993, p. 6) point to some areas that will make research sensitive and pose more threats and create vulnerability of the researched. These include:

- Studies which are concerned with deviance and social control
- Inquiries which exercises coercion or domination
- Research that intrudes into the private lives or deeply personal experiences of the research participants
- Research that deals with sacred things

Nevertheless, there are individuals who are not referred to as vulnerable or marginalized that some researchers in the health and social sciences have also engaged with in their research. They are referred to as the elites or the experts (see Zuckerman 1996; Odendahl and Shaw 2002; Payne and Payne 2004; Stephens 2007; Harvey 2011; Taylor 2011; Mikecz 2012; Williams 2012; Abbink and Salverda 2013; Aguiar and Schneider 2013). They too have particular issues and challenges

that health and social science researchers need to consider in conducting research with them. Elite research is about “studying up.” It is research that involves individuals who have more power than the researcher (Williams 2012; Straubhaar 2015). As Straubhaar (2015) suggests, “elite” is defined as “one who, due to a potentially variable combination of social privileges (on the basis of social class, educational opportunity, etc.), has access to desirable and powerful social networks, through which he or she regularly has the ability to exercise power.”

Neil Stephens and Rebecca Dimond say this clearly in their chapter (► [Chap. 126, *Researching Among Elites*](#)): “Where there is power, there are elites; and there is power everywhere.” Studying up is important as these powerful people are not only “the cause and cure of social problems,” or “may be inefficient or abuse their power,” but they also can “create positive change and social progress” (Williams 2012, p. 1). Chapters written by Neil Stephens and Rebecca Dimond (see ► [Chap. 126, *“Researching Among Elites”*](#)), Jyoti Belur (see ► [Chap. 125, *“Police Research and Public Health”*](#)), and Robert Campbell (see ► [Chap. 127, *“Eliciting Expert Practitioner Knowledge Through Pedagogy and Infographics”*](#)) will illustrate many things that health and social science researchers can learn from.

Sensitive research, Lee (1993, p. 3) argues, stretches beyond the consequences of carrying out the research, but the methodological issues are also inherently essential in doing such research. Lee advocates the need to examine this issue from both the researchers and the researched. As readers will see, Lee’s standpoints have been embraced by several authors in the section. As sensitive researchers, we must make our judgments on the impact of our research on not only the participants but also ourselves as researchers. As such, we must think carefully about the methodology used in collecting their data and the procedures that must be observed as sensitive to research participants, whoever our research participants might be. These are things that are included in chapters in this section.

2 About the Section

This section of the book comprises 18 chapters. In “‘With us and about us’: Participatory methods in research with ‘vulnerable’ or marginalized groups,” Jo Aldridge writes about participatory methods in research with “vulnerable” or marginalized people (► [Chap. 110, *“‘With Us and About Us’: Participatory Methods in Research with ‘Vulnerable’ or Marginalized Groups’*](#)). She argues that most health and social science research that include “vulnerable,” “hard-to-reach,” or marginalized people do not enhance participant engagement and “voice.” For those who claim to use participatory research, the validity of the claims is unclear. Often, “the nature and extent of participant involvement in such studies are not always defined and the value and efficacy, as well as the challenges, of using participatory methods are often misunderstood.” In this chapter, Aldridge explores these issues drawing on her own extensive research with marginalized groups using participatory models which “promote and enhance

participant engagement and emancipation in research processes.” She contends that “such approaches see ‘vulnerable,’ marginalized or socially excluded research participants in transformative roles in research, including as co-researchers, co-analysts and as designers and producers of their own research agendas and projects.”

The chapter on inclusive research (► [Chap. 111, “Inclusive Disability Research”](#)) for disability research is written by Jennifer Smith-Merry. More researchers are becoming involved in inclusive research: research that “people with a lived experience of the field of research under study are included as part of the research team.” In this chapter, Smith-Merry provides an overview of inclusive research with people with disability. Examples from existing projects are illustrated to give a sense of the field and its limitations as well as its possibilities.

Tinashe Dune and Elias Mpofu write about understanding sexuality and disability using interpretive hermeneutic phenomenological approaches in their chapter (► [Chap. 112, “Understanding Sexuality and Disability: Using Interpretive Hermeneutic Phenomenological Approaches”](#)). In particular, the chapter “discusses the rational and processes for applying IHPA to engage participants in these sensitive and complex discussions on their lived experiences of understandings of sexuality.” Procedural guidelines for applying IHPA to studying sexuality with CP as well as the strengths and limitations of this approach are also provided. The authors contend that “IHPA provides a unique advantage to studying health issues with hidden populations or socially sensitive topics with the general population.”

Ethics and practice of research with people who use drugs are presented by Julaine Allan (► [Chap. 113, “Ethics and Practice of Research with People Who Use Drugs”](#)). Effective global harm-reduction strategies aim to prevent or reduce the severity of problems associated with nonmedical use of dependence-causing drugs including alcohol need to fit the personal, social, and environmental context of people using drugs. The best way to develop these strategies is “to research and understand drug use practices including how, why and when drugs are used.” In this chapter, Allan discusses a number of ethical and practical factors to consider when planning and conducting research with people who use drugs. Recruitment of a marginalized and hidden population, gaining consent, ensuring anonymity, and responding to harm and distress are discussed using examples from the author’s research on alcohol and other drug use in rural Australian settings including farming and fishing workplaces, on illicit fentanyl use, and with people in treatment.

Jane McKeown writes about researching with people with dementia (► [Chap. 114, “Researching with People with Dementia”](#)). She contends that doing research with people with dementia has historically been seen as problematic, particularly where there are concerns over the capacity to make decisions and give informed consent among these individuals. She argues that “by not involving people with dementia across the trajectory of the condition, we are failing to develop important understandings from the perspectives of people living with the condition across a range of research topics.” Moreover, by not involving, people

with dementia, them in the research process, “we may not be exploring the most relevant research topics or not considering the most relevant methods and approaches to capture their experiences.” In this chapter, McKeown draws on the evidence base as well as personal experience in the United Kingdom when discussing approaches to consent and approaches and methods that “seek to include rather than exclude people living with dementia throughout the research process.”

Researching with children is presented by Graciela Tonon, Lia Rodriguez de la Vega, and Denise Benatuil (► [Chap. 115, “Researching with Children”](#)). Research with children presents many challenges to researchers, for example, finding methods which are appropriate and interesting to children and which “recognize the importance of children’s experience and agency.” They suggest that these methods “should promote a respectful approach based on ethics.” The chapter discusses “the possibility of using quantitative, qualitative and mixed methods and the emerging of new proposals such as the inclusion of technologies and arts-based methods.”

Optimizing interviews with children and youth with disability is presented by Gail Teachman (► [Chap. 116, “Optimizing Interviews with Children and Youth with Disability”](#)). This chapter provides readers with innovative techniques, strategies, and methods that would engage disabled children and youth in qualitative interviews. In this chapter, a child-interview methodological approach is discussed with “an emphasis on three key elements: assembling a range of customizable interview methods; partnering with parents; and considering of the power differential inherent in child-researcher interactions.” Examples which are drawn from her own research are used to illustrate the methods as well as discuss how they were modified as the research unfolded.

Kat Kolar and Farah Ahmad write about participant-generated visual timelines in their research with street-involved youth who have experienced violent victimization (► [Chap. 117, “Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization”](#)). In this chapter, drawing from a study that explores resilience among street-involved youth, they examined “how participant-created visual timelines inform verbal semi-structured interviewing with persons who have experienced personal victimization in the form of violence, as well as structural marginalization.” They discuss the process of timeline implementation in depth. In their discussion section, they discuss “the potential of visual timelines to supplement and situate semi-structured interviewing” and “illustrate how the framing of research is central to whether that research facilitates increased participant authority in the research process, enhances trust, and ensures meaningful, accountable engagement.”

A feminist application of Bakhtin to examine eating disorders and child sexual abuse is written by Lisa Hodge (► [Chap. 118, “Capturing the Research Journey: A Feminist Application of Bakhtin to Examine Eating Disorders and Child Sexual Abuse”](#)). Drawing from her research which explored the nature of the relationship between women’s experiences of child sexual abuse and eating disorders, Hodge demonstrates how Bakhtin’s theoretical constructs can “expose

the hidden mechanisms of control found in these gender-based oppressive practices.” She also shows “how drawing and poetry, when used in qualitative research methodologies, can create space for interactional discovery and give voice to the unspeakable.”

Lizzie Seal discusses feminist dilemmas in researching women’s violence (► Chap. 119, “[Feminist Dilemmas in Researching Women’s Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise](#)”). She contends that the use of violence among women is a sensitive topic for feminist researchers. This is “because feminists have sought to delineate the role of male violence in continuing women’s subordination.” Highlighting women’s violence can detract from this position. She argues that “researching women’s violence using feminist methodologies, which place value on creating knowledge from women’s experiences, hearing marginalized voices and democratizing the research process, raises dilemmas.” In this chapter, Seal considers these dilemmas across three areas – questions of allegiance, questions of representation, and questions of ambivalence and compromise. A number of examples are highlighted in order to illustrate these issues.

Andi Spark presents a very interesting discussion regarding researching in the animated visual arts and mental welfare fields (► Chap. 120, “[Animating Like Crazy: Researching in the Animated Visual Arts and Mental Welfare Fields](#)”). She argues that her research “straddles the divide between creative arts practice and social science methodologies, with a focus on outlining a practical approach to developing short-form mixed-media format animated projects that address serious issues such as postnatal depression.” This chapter discusses “how animation can be utilized for both communicative, informative and entertaining purposes.” In order to deliver authentic and authoritative projects for a targeted audience, Spark explains “how animation works in emphasizing symbols and metaphors to elicit empathetic responses” using a number of examples from other independent creative practitioners.

Researching underage sex work is written by Natalie Thorburn (► Chap. 121, “[Researching Underage Sex Work: Dynamic Risk, Responding Sensitive, and Protecting Participants and Researchers](#)”). This chapter tells us the challenges inherent in her own experience of undertaking research with adolescent sex workers who have experienced complex trauma histories. The chapter also discussed the “dynamic nature of risk as it relates to research with vulnerable populations, particularly in regard to physical safety, emotional and psychological safety, consent, confidentiality, and interpersonal power within the research relationship.” Strategies of identifying and managing these risks are provided in the chapter.

Lauren Rosewarne writes about the Internet and research methods in the study of sex (► Chap. 122, “[The Internet and Research Methods in the Study of Sex Research: Investigating the Good, the Bad, and the \(Un\)ethical](#)”). She contends that “the Internet has thoroughly revolutionized sex.” The technology has become a key source for individuals to explore sexuality and participate in the erotic activity. For researchers, the Internet has provided great “access to academic databases and

archives, to social media sites and public diaries, and notably to a world of possible research participants, in turn dramatically altering the ways sex gets studied.” In this chapter, drawing on a wide range of literature on research ethics as well as her own background as a sex researcher, an author of the Internet research, a supervisor of research students on new media, and a long-time member of her university’s human ethics committee, Rosewarne outlines, analyzes, and problematizes the use of the Internet in sex research that we can learn from.

Emotions and sensitive research are presented by Virginia Dickson-Swift (► [Chap. 123, “Emotion and Sensitive Research”](#)). Researching sensitive topics is often an emotional journey, not only for the participants but also for others that may be involved in the research. The emotional challenges that researchers face when doing fieldwork cannot be ignored. Drawing on her earlier empirical work with researchers in Australia and published accounts, Dickson-Swift provides an overview of the emotional challenges inherent in this type of research. She also provides suggestions for researchers, research supervisors, and others involved in the research team. She suggests that these suggestions can be adopted by academic or research institutions to ensure that researchers have the necessary support to conduct sensitive research.

Doing reflectively engaged, face-to-face research in prisons is written by James E. Sutton (► [Chap. 124, “Doing Reflectively Engaged, Face-To-Face Research in Prisons: Contexts and Sensitivities”](#)). Sutton provides “fundamental features of prisons and prisoners’ lives” which make them “sensitive settings and populations for researchers to study.” He then presents ethical issues that researchers need to be mindful of when conducting research in prisons. Ultimately, the chapter “endorses being reflectively engaged with the setting, the research process, and oneself when doing face-to-face research in prisons, regardless of the substantive goals of one’s study or the particular research methods one employs.” Sutton contends that the issues raised in this chapter will be valuable to health and social science researchers who enter prisons to study prisoners.

Jyoti Belur writes about police research and public health (► [Chap. 125, “Police Research and Public Health”](#)). The chapter discusses the challenges in conducting face-to-face research with police officers regarding their work in sensitive areas or with hard-to-reach groups. She suggests that the “changing nature of policing” and “a rise in societal demands for security” have resulted in the “overlap between law enforcement and public health.” In this chapter, based on her personal experience and drawing upon the research experience of others working in this area, Belur provides some basic guidelines to assist researchers who work in this space. She identifies fundamental features of policing culture which make it “a sensitive organization to access and research.” She then discusses “the difficulties in approaching gatekeepers and negotiating access to police data and individual officers.” Ethical and practical considerations in carrying out police research are also discussed in this chapter.

Researching among elites is presented by Neil Stephens and Rebecca Dimond (► [Chap. 126, “Researching Among Elites”](#)). Often, health and social science researchers conduct research with those who have less power than them. But the

authors argue that researchers should also engage with those who are seen as the “health elites” as they are “powerful actors in the medical domain.” However, there is a specific set of methodological challenges that involve in doing this kind of research. In this chapter, drawing on their own research practice, the authors discuss several main issues and challenges that researches need to consider before undertaking research with health elites. They argue for the continued need for qualitative social science to engage with health elites and also for researchers “to be informed by methodological awareness of the challenges and rewards of doing so.”

In the last chapter of this section, Robert H. Campbell writes about eliciting expert practitioner knowledge through pedagogy and infographics (► Chap. 127, “Eliciting Expert Practitioner Knowledge Through Pedagogy and Infographics”). Campbell suggests that qualitative research routinely obtains knowledge of expert professionals. However, eliciting tacit or implicit knowledge effectively can be problematic. In this chapter, Campbell discusses a method in which pedagogy and infographics were combined to elicit the knowledge of expert practitioners. The focus of the chapter is on the underpinning principles and deployment of the method. He suggests that this approach can be easily transferred into a range of qualitative research domains.

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“With Us and About Us”: Participatory Methods in Research with “Vulnerable” or Marginalized Groups

110

Jo Aldridge

Contents

1	What is Participatory Research?	1920
2	“Vulnerability,” Marginalization and Enhancing “Voice” in PR	1922
3	Towards a Participatory Model	1926
4	Principles of Participation	1930
5	Conclusion and Future Directions	1932
	References	1933

Abstract

In much health and social scientific research that includes “vulnerable,” “hard-to-reach” or marginalized groups, claims are often made about participatory methods and techniques that enhance participant engagement and “voice.” In many cases, however, the validity of these claims remains unclear – the nature and extent of participant involvement in such studies is not always defined and the value and efficacy, as well as the challenges, of using participatory methods are often misunderstood. In many respects, these oversights can be explained by the lack of cognate *and* applicable participatory models or frameworks that can help researchers work more effectively *with* marginalized participants. This chapter explores these issues drawing on the author’s own extensive research with marginalized groups and participatory models of working that both promote and enhance participant engagement and emancipation in research processes. Such approaches see “vulnerable,” marginalized, or socially excluded research participants in transformative roles in research, including as co-researchers, co-analysts, and designers and producers of their own research agendas and projects.

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Participatory research · Vulnerable groups · Participant voice · Social exclusion

1 What is Participatory Research?

In their 1995 review of participatory research, Cornwall and Jewkes asked a key question: “If all research involves participation, what makes research participatory?” (p. 1668). This question is perhaps even more pertinent today given the increasing interest in, and use of, participatory research (PR) methods in social (and health) sciences since its emergence in the 1970s and its relevance for working more effectively with “vulnerable” or marginalized groups. Nevertheless, despite advances made in PR over the past four decades, and the claims made for it in terms of working more successfully with marginalized participants (using methods that enhance participation), the call for greater theoretical and methodological rigor in PR remains pertinent (see Chevalier and Buckles 2013). In part, this is due to the lack of formal participatory models or frameworks that help lend clarity and validity to PR, as well as serve to demonstrate more precisely the link between PR and working effectively with marginalized individuals or groups. Therefore, questions such as *what makes research participatory?* and *how can PR be used effectively to enhance participation among marginalized participants?* are perhaps even more pertinent today than they were four decades ago.

Since the 1970s, new approaches to research, particularly in the qualitative field, facilitated more creative methods of investigation (see chapters in the “Innovative Research Methods in Health Social Sciences” Section). The result was that more diverse and inventive empirical approaches began to flourish across a range of different disciplines that also enabled researchers to address issues such as the meaning of, and relationship between, vulnerability, inclusion, and participation in research – although the connection and congruence between these concepts were not always made explicit in research design and discourses; to some extent this is still the case today. One of the reasons for this is that the terms “participatory research” and “participatory action research” (PAR) are often not fully understood, or exaggerated claims are made for studies that (may or may not) use these kinds of methods. PR is a broad umbrella term under which a number of participatory, collaborative, or inclusive research methods and approaches are located. PAR, on the other hand, emerged in the 1940s following the pioneering work of Kurt Lewin and the Tavistock Institute (see Chevalier and Buckles 2013) and focuses specifically on *social change* outcomes for participant groups, organizations, or communities (as opposed, specifically, to individuals) through *action* research. Ongoing developments in PAR have seen a diversity of approaches and techniques emerge in the qualitative field, including, for example, participatory rural appraisal (PRA) and participatory learning and action (PLA) and demonstrating, “a well documented tradition of active-risk taking and experimentation in social reflectivity backed up by evidential reasoning and learning through experience and real action”

(Chevalier and Buckles 2013, p. 4) (see also ► Chap. 17, "Community-Based Participatory Action Research").

Chataway's (1997) study with indigenous communities of North America is a good example of the PAR approach, which embraced principles of collaboration and mutuality. Focusing specifically on issues of identity, security, and self-government, Chataway adopted a PAR approach through the use of focus groups and intergroup discussions, and enabling community participants to draw on "non-native" research strategies to identify reasons for community divisions and the barriers to change. Given the level of political oppression, the indigenous population had experienced under "Euro-American dominance," and the subsequent distrust of "outsiders" within communities, the researchers were required to be flexible and adaptable with respect to PAR approaches and methods. They understood that the study needed to be both "internally directed" as well as in the best interests of the participants if it was to be successful. Chataway (1997, p. 748, emphasis added) concluded that without a PAR approach, "we would not have been able to overcome the barriers to research in this context. With PAR, we were able to complete four successive pieces of *collaborative* research." For a full discussion about different kinds of PAR approaches, see Chevalier and Buckles (2013).

The intention of PR more broadly – both conceptually and philosophically, for example – is to promote greater inclusion and collaboration in research and to recognize and give credence to the voices of *individuals* both within and outside communities (see Fals Borda 1988; Whyte 1989; McTaggart 1997; Goodley and Moore 2000; O'Neill et al. 2002; Aldridge 2007, 2012a, b; Higginbottom and Liamputtong 2015). Thus, PR draws on philosophical principles and objectives that relate to mutuality and understanding in research practices and which are "designed to promote active involvement" in the research process by participants who, in studies that use more conventional methods, may be treated simply as the objects of research (Chataway 1997, p. 747; see also Fals Borda 1988; Whyte 1989; Bourdieu 1996; McTaggart 1997). Rapoport's participatory research in the 1970s (1970, p. 499) demonstrated both the distinction and advantages of PR compared to other qualitative methods in the ways in which it facilitated the active involvement of researchers and participants in research processes, with a specific focus on "joint collaboration with a mutually acceptable ethical framework."

Although the different types of research methods used in PR (and PAR) studies can be diverse and often also adopt and adapt techniques from other disciplines and practices (see Higginbottom and Liamputtong 2015), the fundamental difference between PR and other research methodologies lies in "the location of power in the various stages of the research process" (Cornwall and Jewkes 1995, p. 1667). Further, the stories and "voices" of participants are placed center stage, both in the design and objectives of PR studies. Walmsley and Johnson (2003, p. 10) recognize the methodological diversity in PR studies that have been described variously as "participatory, action or emancipatory," but all of which have a common objective and intention to engage participants in more empathic and democratizing research relationships. Walmsley and Johnson describe this type of approach, as well as their own PR with people with learning difficulties, as "inclusive" research, where

participants “are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research” (2003, p. 9; see also Atkinson 1986; Flynn 1989).

O’Neill et al. (2002, p. 69) have pointed to the ways in which PR methods have helped to “transgress conventional or traditional ways of analyzing and representing research data” at a time when ideas about “hard-to-reach” or marginalized groups in research, as well as in health and social care discourses, were also changing. Since the development of PR four decades ago, and certainly more recently, greater emphasis has been placed on the needs of “socially excluded,” “vulnerable,” or “marginalized” people in research, many of who would have been overlooked or excluded from research in the past because they were deemed too “difficult” to reach and include (see Liamputtong 2007; see also ► Chaps. 99, “Visual Methods in Research with Migrant and Refugee Children and Young People,” and ► 100, “Participatory and Visual Research with Roma Youth”).

However, despite these methodological advances and the opportunities offered by PR, critical questions still remain, not least about the nature and extent of participation in PR studies, and especially in those that do not make reference to formal participatory frameworks or models, or to the (participation) needs of vulnerable or marginalized populations. It is important to note, however, that not all research with vulnerable or marginalized groups is participatory in design or intent, nor necessarily aligns itself with PR or PAR objectives; neither are participatory methods only used among “vulnerable” respondents. Additionally, not all research that lays claim to an inclusive, participatory agenda promotes the principles commonly associated with participatory approaches, such as understanding, mutuality, emancipation, collaboration, and giving “voice.” In which case, it is necessary to explore the relevance of, and alliance between PR and working with vulnerable or marginalized individuals or groups in research much more closely, and specifically regarding the ways in which individual and collective “voices” are facilitated and heard in PR methods and research praxis.

2 “Vulnerability,” Marginalization and Enhancing “Voice” in PR

When considering the role and efficacy of PR in research that involves vulnerable or marginalized participants, it is necessary to clarify what is meant by “vulnerability” both definitionally and conceptually. In many respects, “vulnerability” remains a mutable, even contestable, concept and especially when considering the various definitions and classifications adopted in research governance and ethical frameworks, in health and social care discourses, and with respect to the perceptions of those people defined as “vulnerable.” It is also clear that in some studies, even though claims are made about working inclusively with vulnerable people using PR techniques, vulnerability as a concept is not always defined nor explained in sufficient detail to demonstrate clearly the connection between participatory research objectives and research praxis.

In her work on vulnerable groups in health and social care, Mary Larkin (2009) notes the extensive use and relevance of the term "vulnerable" both conceptually and in practice, but also recognizes that a precise definition remains "elusive," acknowledging that "its meaning also varies according to the context in which it is used" (p. 1). This is evident both in the various and sometimes inconsistent definitions used in health and social care discourses – where it is most often used to denote susceptibility to harm or risk, for example, or as an indicator of enhanced need – and in research governance frameworks where, for example, lack of capacity for self-care determines a person's vulnerable status (see, Department of Health 2000, Sect. 2.3) and where individuals are often grouped together under more general categories of vulnerability, for example, people with mental health problems, people with disabilities, and people in prison. Twenty years ago, Rogers (1997) was more "inclusive" in his definition of vulnerability, which included the "very young" and the "very old," those susceptible to illness, black and minority ethnic (BME) groups, people on low income or who were unemployed, as well as women. Since that time, the term "vulnerable" has been assigned to groups of people who, for example, lack the capacity for self-protection, for developing resilience or effective coping strategies (see Parrott et al. 2008), or who "lack the ability to make personal life choices, to make personal decisions, to maintain independence and to self-determine" (Moore and Miller 1999, p. 1034; see also Liamputtong 2007).

In terms of research governance and ethical frameworks, in the UK, the Department of Health's (2005) *Research governance framework for health and social care* emphasizes participants' capacity and willingness to provide informed consent as well as describes vulnerable or potentially vulnerable participants as children and adults with mental health problems or learning difficulties. Economic and Social Research Council (ESRC 2010) descriptors, on the other hand, focus on research that puts participants at "more than minimal risk" and "potentially vulnerable groups" as children and young people, those with learning difficulties or cognitive impairments, those who lack the mental capacity to give consent, and "individuals in a dependent or unequal relationship" (p. 8).

Helpfully, in her health and social care research, Mary Larkin makes the distinction between someone who is individually, uniquely, or innately vulnerable (through chronic illness or disability, for example) and those who are vulnerable because of their circumstances, environment or as a result of structural, systemic factors. It is worth noting, further, that subjective, self-perceptions of need may not always accord with objective or external identifiers or classifications of vulnerability. Steel (2001, p. 1), for example, acknowledges that some people, "would not describe themselves as vulnerable or marginalised at all," and that self-perceptions of vulnerability are both socially constructed and again, contextual – "[it depends on] where you are standing at the time, and in relation to who, or what."

From a research governance and ethical perspective, however, individual self-perceptions of vulnerability or marginalization, and philosophical debates about such concepts, are unimportant; what is important is that research participants themselves are not put at further risk of harm or their vulnerability exacerbated by research processes and that researchers and institutions are equally protected.

Thus, research governance frameworks and ethical guidelines provide extensive advice and guidance about the type and extent of ethical clearance required in order for research studies that include vulnerable or marginalized groups to proceed. For some researchers, this is welcome; for others, there are concerns that strict ethical regulation may serve to further exclude vulnerable or marginalized individuals and groups from having their voices heard, or from being included in research studies in the first place (Boddy and Oliver 2010; Hurdley 2010).

Despite these arguments, it is important that researchers are conversant with and understand issues and debates relating to vulnerability and marginalization when planning research studies with participants who may have particular and distinct needs and thus who may also require different kinds and levels of participation. It is equally important that researchers consider carefully the link between vulnerability (or marginalization) and research participation with respect to developing a clear understanding of equality and power in research relationships; what is central to the relevance of, and relationship between, the participatory project and working effectively with vulnerable or marginalized people – both in terms of research processes and outcomes – is the intention to address inequality and powerlessness by giving “voice” to individuals who may otherwise be overlooked or excluded from research. Individuals such as those with mental health problems or learning difficulties, for example, are often denied full participation in public or political life and can be overlooked in research studies that adopt more conventional, non-PR approaches simply because they are deemed hard to access or to recruit on to research projects (see Aldridge 2012b).

This is why the notion of “voice” should both inform and underpin PR approaches in social scientific and health research (as well as in other fields and disciplines), as a way of ensuring the experiences of participants are located center stage in research agendas and processes by enabling participants to speak or “tell” their individual or collective stories in their own ways – that is, in ways that are deemed most appropriate to each individual or group. Notably, “voice” in this context can be understood and interpreted in different ways – theoretically, culturally and/or politically, for example. Equally, a number of different methodological approaches are available to the participatory researcher keen to enhance participant “voice”; for example, participatory visual or narrative methods, life history research, diary methods, and so on. A good example of the first of these is Thomson’s (2008, p. 3) visual research with (vulnerable) children and young people in which visual techniques (photography and video, for example) are used in order to “find ways to bring previously unheard voices into scholarly and associated professional conversations.” Working with Britzman’s (1989) multiconceptual understanding of “voice” (literal, metaphorical, and political), Thomson recognizes the importance of conferring competency and agency on (vulnerable) children and young people – of “giving voice to the voiceless” (Britzman 1989) – by engaging with them in more direct and inclusive ways using less conventional methods. For Thomson and her colleagues, the use of participatory visual research methods presents valuable opportunities for involving children as the co-producers of research – by giving them cameras, video equipment, art materials, and so on in order to collect their own evidence (see also

► Chaps. 99, "Visual Methods in Research with Migrant and Refugee Children and Young People," and ► 100, "Participatory and Visual Research with Roma Youth").

Other participatory methods which have borrowed techniques from visual sociology, for example, in order to enhance participants' visual "voices" and to work more inclusively with marginalized individuals and groups, combine the visual with first-person oral or written accounts and introduce a range of techniques, including photographic diaries, photovoice techniques, and photographic elicitation methods (Aldridge 2012a, 2015; see also Sempik et al. 2005; Aldridge and Sharpe 2007; Joanou 2009; Catalani and Minkler 2010; see also ► Chap. 65, "Understanding Health Through a Different Lens: Photovoice Method"). The intention here is not just to uncover new insights into lived experience and needs that other more conventional methods might miss, but also to foster understanding and more empathic *responses* – from the audience/reader as well as the academic researcher – to the visual and narrative "voices" of participants who might otherwise be overlooked or excluded entirely from research.

A good example of this kind of empathic testimonial approach is Rapport's (2008, p. 1) in-depth "research conversation" with survivors of the Holocaust. Rapport used a combination of poetic (textual) and photographic narrative methods in order to take both the reader and the researcher on a textual-visual journey. Her objective – congruent with Bourdieuean concepts of understanding and mutuality in research – was to develop greater in-depth understanding of the researcher–participant relationship as well as research processes, including in the final output and communication phase. She described these revelatory aspects of the study as a process of "coming to know" the data and argues that this approach makes visible "what is often invisible in more traditional approaches" (2008, p. 1). Without a doubt, the combination of the visual and the prose or poetic-style of the personal survivor narratives are compelling and engender an emotional as well as empathic response in the reader/viewer that may be missed by other more conventional research methods. The photograph of the barracks and execution wall at Auschwitz, for example, with its austere and imposing red brick façade and enclosed dirt yard, taken by Rapport herself, coupled with the personal narratives of the survivors – written *by them* – are both compelling and intuitive testimonials of the survivor experience.

My own area of research has focused on working exclusively with vulnerable or marginalized research participants, including individuals with little or no connection to known communities of support (either formal or informal). In many cases, visual methods work well in terms of facilitating participants' engagement in research as data collectors and analysts – in short, as co researchers. Two of my participatory visual studies included participants who were either unable (due to profound learning difficulties) or unwilling (children who did not want to speak about their experiences) to engage with conventional qualitative methods such as interviews or focus groups and took part in photographic diary and elicitation methods that invited them to act as data collectors and analysts (see Sempik et al. 2005; Aldridge and Sharpe 2007; Aldridge 2014). The photographic diary method used in both studies engaged participants as photographers to enable them to demonstrate their experiences visually and to highlight needs that other studies might have missed.

In the first, 2005, study (Sempik et al. 2005), 19 people with profound learning difficulties who attended gardening projects across the UK were invited to take photographs (using disposable cameras) that were meaningful to them on site at the projects over a 2-week period. The photographs were developed and given to the participants to keep but were also used in visual “conversations,” using the images as visual prompts in order to “tell” or show a story about project participation. The participatory visual method was critical in this study as a way of enhancing participant inclusion and action – participants took on the roles of data collectors and (to some extent) analysts – in the research process (for further discussion, see Aldridge 2012a, b).

The second, 2007 (Aldridge and Sharpe 2007), study used the same participatory photographic methods (again, over a 2-week period) with 16 children and young people who lived with and cared for parents with serious mental health problems. The children were invited to take photographs of aspects of their lives that were meaningful to them. Again, the photographs that were produced were used in the elicitation phase of the study where the children and young people engaged in selecting particular images and telling their own visual story (the story they wanted to “tell” and show) about what life was like living with and caring for a parent with a serious mental health problem. Both studies used participatory visual methods as part of a multimethod approach and generated visual data that gave important new insights into the lives of marginalized participants. The photographic method itself was also highly effective in engaging participants who might otherwise be left out of research because conventional methods would not suit or meet their needs. Following completion of both studies, photographic methods were adopted in professional practice (at both gardening and young carer projects in the UK) as a way of engaging with new service users/clients in more meaningful ways.

3 Towards a Participatory Model

Despite the efficacy and relevance of these kinds of “bespoke” participatory visual methods in PR, it is critical that new and future PR studies make clear reference to participatory frameworks or models of working that help lend validity and credence to PR methods and that also enable both researchers and participants to locate their approaches within a clear methodological frame of reference. Without this, research studies that use PR methods are in danger of remaining firmly on the margins of empirical investigation and thus may make only limited contributions to knowledge. However, only a limited number of PR models/frameworks have been available to the participatory researcher in the four decades since its development in the 1970s. Some early pioneers of PAR and PR methods proposed typologies or frameworks that enabled researchers to reflect to some extent on the efficacy of their own participatory approaches. For example, in the late 1980s, drawing on his research in agriculture, Biggs (1989) proposed four modes of PR that included contractual, consultative, collaborative, and collegiate phases in the participatory research process. Six years later, Cornwall and Jewkes (1995, p. 1669) offered some refinements

to these modes to include "shallow" and "deep" participation, where researchers in the former mode controlled the research process but relinquished some of that control to participants in the "deep" phase. Hart's "Ladder of Participation" model (1992) for working more effectively with children and young people in research included seven distinct stages, with "manipulation" at the bottom of the Ladder – where participants in research: "do or say what adults suggest they do. They have no real understanding of the issues, although they may be asked for their views. They do not know what influence their views will have on any decisions that are made" (p. 8). At the top of Hart's Ladder, PR is much more emancipatory and is delineated by both control and ownership, where participants take on the role of researcher, initiating, designing, and conducting research themselves.

In terms of working more effectively with vulnerable or marginalized groups, any PR model or framework should enable researchers (whether they are academic, advocate, or participant researchers) to "locate" their own position, and role, in the research process as well as those of research participants. The Participatory Model (PM) in Fig. 1 is constructed from a participant-oriented standpoint – and is presented very much as a continuum, one that always works away from treating the research participant as object – and is intended as an aid to researchers (both within and outside the academy) who are planning or reflecting on the use of participatory methods with different participant populations, including vulnerable,

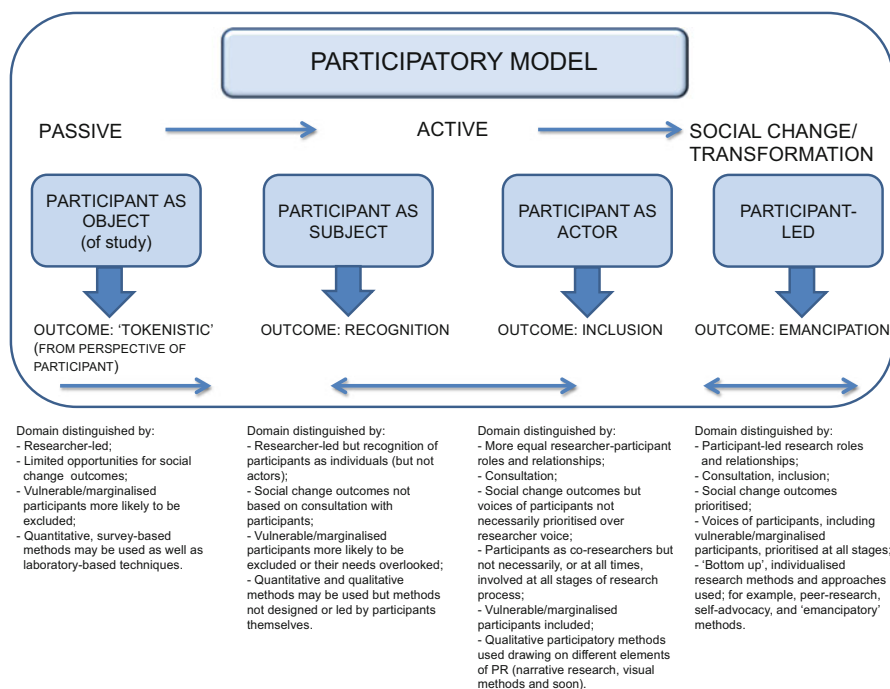


Fig. 1 Participatory model

marginalized, or socially excluded people. The PM is also intended to help promote participant emancipation and “voice” in qualitative research by encouraging researchers to reflect more carefully on research relationships and the ways in which they may work *with* participants as *actors* in research (thus, in research that, from a participant standpoint, is both “*with* us and about us”).

Rather than working within a strict set of research *rules*, the PM also requires researchers to recognize and adhere to a number of *principles* (see below) and objectives when conducting PR. As has been stated, the principles of participation in PR should ensure greater equity in researcher–participant relationships (including and particularly when participants are vulnerable, marginalized or socially excluded), and engagement in dialogue with participants – about research design, ethics outputs and so on – should be part of an ongoing process throughout the duration of any PR study. Such studies should always be designed from the outset with the needs of participants in mind. As has been discussed, under the somewhat broad qualitative research umbrella, a number of different PR methods can be effective, including participatory narrative or life story methods and those produced in visual form, including visual-textual and autobiographical methods, for example (see Atkinson 1997; Aldridge 2015). These kinds of methodological techniques that reconstruct and articulate subjective experience as spoken, written, or visualized narratives produced by participants themselves can, as Goodson argues (2013, p. 30), serve as “a starting point for developing further understandings of the social construction of each person’s subjectivity.” These types of participatory story telling/showing (*autobiographical*) methods, while sometimes difficult for some people to initiate themselves or see through to publication or output phases on their own, may, as Walmsley and Johnson (2003, p. 149) argue, nevertheless also “[hold] the greatest potential for full and equal partnership.” This is because such methods and approaches emphasize and promote the participant-as-narrator as the expert or “ultimate insider” (Walmsley and Johnson 2003, p. 149).

In some cases, of course, truly “emancipatory” research may be out of reach, inappropriate, or even irrelevant for some participants. Simply talking about their experiences, in interviews or focus groups, for example, may be sufficient and even welcomed by some research participants – it is important not to assume, for example, that even when participants may be considered “vulnerable” or marginalized, they may wish to design and lead their own research projects about their lives and/or the lives of others. What is important to remember is that “bespoke” methods in PR should be designed from the bottom up, that is, with the needs of individuals (or groups of individuals) in mind and that consultation with participants about their needs and their roles and relationships in research processes should form part of an ongoing process in any PR study – these are some of the key principles and components of the PR approach.

As has already been stated, not all research that adopts participatory methods lays claim to or aligns itself with a strict or clearly defined participatory approach. On the other hand, some PR studies make participatory claims without explaining or being clear about the nature, extent, and limitations of participant involvement. This is clearly unhelpful in terms of promoting PR as a way of building better and more democratic research relationships. With respect to advancing PR theoretically and also in lending methodological credence and validity to the PR approach, it is equally

unhelpful when researchers have to search – sometimes in vain – for participatory indicators in descriptions of research studies that claim to use and promote inclusive or emancipatory ways of working but do not make either the *principles* of PR, or the research *process*, clear. The kinds of participatory methods used in PR, as well as the design and context of the research itself, and the relevant theoretical underpinnings, should be clear from the outset in any PR project; as should the ways in which participatory and, where relevant, emancipatory principles and objectives will be achieved through working collaboratively and inclusively with participants.

Part of this inclusive process must also ensure avoidance of research that is tokenistic or simply pays lip service to participatory or emancipatory principles or objectives. Thus, credible and reliable PR must include careful consideration of the best and most appropriate ways in which experiential (life story) evidence can be garnered, analyzed, and represented (as opposed to re-presented; see Aldridge 2015, 2012b). Lewis and Porter (2004, p. 196) argue that where researchers are committed to “giving voice” in research, then the process also demands “careful planning, preparation and the apportioning of appropriate time,” as well as the need to “keep asking ourselves what trust we can place in our methods and check we have not overly predetermined the views that we have encouraged to be heard.”

This also means that academic researchers need to demonstrate commitment not only to research participants (as well as in most cases to the academy and to research funders; see Aldridge 2012b), but also to developing and advancing PR methods in order to enhance the credibility and rigor of these kinds of qualitative approaches. It is acknowledged that studies that use less conventional, more creative and inventive qualitative techniques are not so readily accepted for their empirical or “scientific” value in all policy contexts and in some disciplinary settings. Walker et al. (2008, p. 164) argue, for example, that “the world of policy and practice tends to be more cautious in its response” to this type of evidence.

Thus, there is even greater need for PR to achieve the kind of rigor and cohesion that has been called for in other related disciplines and fields. In the late 1990s, Liebllich et al. (1998, p. 1) proposed that narrative research methods, for example, required “a deliberate investment of effort in the elucidation of working rules for such studies.” I would argue that this same kind of investment is required in order to advance PR both methodologically and theoretically, but with an equal emphasis on the *principles* and *models* of working rather than on strict “rules” or formulas.

Without such models of working, there is a real danger that unrealistic or even half-hearted attempts will be made to work more collaboratively and inclusively with specific participant groups (including vulnerable or marginalized participants), thus further undermining the credibility of PR methods. Although in recent years important advances have been made in PR and in working more empathically and inclusively with people who have traditionally been left out of research studies, there is currently even greater need for care and attention to advancing both the principles and mechanisms of PR; arguably, during times of such serious fiscal retrenchment, it is even more likely that research studies that are not considered sufficiently “scientific” or “credible” may be at even greater risk of being overlooked in a competitive and increasingly restrictive funding environment.

It is in these contexts that the needs of vulnerable or marginalized people need to be considered carefully and sensitively by PR investigators (from both within and outside the academy) in order to ensure that they are included in “bespoke” PR studies as well as, where appropriate, in more “mainstream” studies that can accommodate or allow for a degree of methodological flexibility. Incorporating qualitative methods and, more specifically, clearly defined and designed PR techniques as part of a multimethod approach is one way of achieving this. This would ensure that those who have traditionally been left out of, or have had very little input into, research or public policy decision-making processes could be included in ways that, as Hill et al. (2004, p. 78) argue, “meet their wishes and felt needs” through “multidimensional participation.”

The PM above (Fig. 1) is relevant and applicative in the context of both stand alone, “bespoke” PR studies and for those that are part of larger, more conventional, or “mainstream” multimethod projects. The underlying principle in PR, however, is that in each case research should always move *away from* tokenistic methods that treat participants as (passive) objects (the “participant as object” domain in the PM). Thus, the PAO domain is included only in order to serve as a point *from* which PR should always advance. At the same time, the PM can accommodate different levels of PR approaches, recognizing that it is not always possible for research to be solely “emancipatory” and participant-led (PL; Fig. 1) – some research, for example, may be designed with little or no consultation with participants, but may then involve further new or adapted elements of participation at a later stage, either through greater collaboration with participants during fieldwork phases or during the outputs phase. Thus, some research may contain participatory elements, where participants are treated as individual subjects (“participant as subject” on the PM), as well as other participatory elements (across the domains) that facilitate closer collaboration in research processes and relationships (e.g., the “participant as actor” domain). The PL domain prioritizes social change outcomes as well as methods and approaches that facilitate and promote participant voice, self-advocacy, and emancipation. PR studies that are located and operate within this domain should, wherever possible, be designed and led by participants themselves.

The PM has also been designed as a guide for researchers who are planning future PR projects, but it can also be used to evaluate past and current studies. When considering the two participatory visual projects described in this chapter with reference to the PM, we can see how both the young carer/mental health and the gardening studies are more clearly located in the PAA domain, but also with some elements borrowed from the PL domain – the purpose of the PM is to allow for such crossovers, or fluidity of movement within and across the model, *as long as the points of designation and intersection are made clear*.

4 Principles of Participation

The PM provides researchers with a point of reference and an opportunity to consider more carefully both the principles (see below) and processes involved in their own participatory approaches – locating, designating, and identifying points of

intersection within and across other domains is, for example, an important part of the PR process, as discussed above. The PM also gives researchers the chance to consider more carefully the participatory claims that are made in other research studies that purport to be participatory in nature and intent. While such claims should be explained and verified through careful explication of the nature, extent, and limitations of the kind of participation involved (the PR process), it is clear that this is not always the case. Reference to a clearly designed participatory framework, typology, or model, such as the PM described and discussed in this chapter, would undoubtedly help in this respect. For those researchers who are thinking about or planning PR, and particularly with vulnerable or marginalized participants, moving away from research that is tokenistic and which treats participants simply as objects, and even as subjects, in research (the PAO and PAS domains in the PM) would help advance PR methods and approaches that are delineated clearly by their emphasis on inclusion, collaboration and emancipation (wherever the latter is possible). With these issues in mind, the following principles are proposed as a further guide or reference point for researchers (both within and outside the academy) when thinking about and planning participatory projects. In these contexts, PR should:

- Be designed with the needs of participants in mind – it should take account of the needs of participants, their conditions, and circumstances (including the nature and extent of their vulnerability or marginalization, as well as social exclusion factors, where relevant).
- Involve a process of ongoing dialogue and consultation; this should include discussion of research design issues, the needs, and rights of participants, and how “voice” is facilitated and can lead to transformative outcomes, as well as ethical issues and requirements.
- Ensure research relationships are based on mutuality, understanding, and trust and, depending on the nature and extent of the participatory principles and objectives involved (what is achievable and realistic in research terms), that the voices of participants are prioritized over those of academic researchers.
- Be clear about the opportunities for participation, as well as the extent and limitations of the participatory approach, so that research projects do not raise unrealistic expectations for participants or make false participatory claims. It is essential that PR projects are clearly defined with respect to participatory typologies or participatory models/frameworks.
- Ensure participants are given opportunities to reflect on their engagement in research projects, as well as the level/extent or limitations of the participatory methods and approach. In this way, the views of participants must “inform the link between social inclusion and participation” (Hill et al. 2004, p. 80). Academic researchers may also want to be reflexive about research processes and relationships in order to make useful contributions to contemporary methods debates and discourses.
- Be sufficiently flexible so that participatory techniques may be included in larger, mainstream, multidimensional studies. PR methods can be effective in studies that adopt multimethod approaches, and this is especially the case when less

conventional PR strategies are used and when working with vulnerable or marginalized people.

- Recognize that vulnerability (or marginalization) is both a mutable and contestable concept and that for most people, this is not a fixed identity or condition. PR should address vulnerability in this way and attempt to redress the impact of marginalization and/or social exclusion, for example, through transformative objectives.
- Recognize that transformative outcomes in PR can be personal, social, political, and so on and may occur immediately, indirectly, and/or over time.
- Recognize that the data collated and/or produced by participants in PR can be subject to different kinds of analyses, interpretation, and reflexive processes; these should serve to enhance participant “voice” and ensure that participants are not just treated as the objects of research, but are also considered as co-researchers, collaborators, disseminators, “doers,” and self-advocates within what is realistically achievable in PR terms.

5 Conclusion and Future Directions

When considering the ways in which greater clarity and methodological rigor can be brought to PR, what is missing from many studies that make participatory claims, as discussed, is recognition of the nature, extent, and limitations of participation within individual projects and for specific individuals or groups of participants. Without such rigor, clarity, and focus in PR studies, the voices of “vulnerable” or marginalized individuals or groups may continue to go unheard. While various participatory typologies and models of working have been described and proposed in PAR specifically (see Biggs 1989; Hart 1992; Chevalier and Buckles 2013), few attempts have been made to evaluate their efficacy, use, and relevance in the field, particularly by participants themselves, or to bring these together under a broader PR banner. Neither do many studies that make participatory claims always align themselves with specific participatory models or frames of reference.

The PM discussed in this chapter has been developed with the intention of addressing some, if not all, of these issues and oversights by providing a participatory framework for researchers (from both within and outside the academy) to locate their own participatory projects with reference to the various domains within (and across) the model. Drawing extensively on my own experiences of conducting PR or participatory-type projects, as well as evidence from a wide range of research studies in my own and other fields, the PM has been designed for the purpose of helping researchers more clearly align or define their PR projects with reference to, or across, a particular domain or domains within the model itself. An additional intention of the PM is to advance PR as a credible and constructive approach to working more effectively with participants who may not readily or obviously fit within the boundaries of conventional research participation.

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Inclusive Disability Research

111

Jennifer Smith-Merry

Contents

1	Introduction	1936
2	How Inclusive Is Inclusive Research?	1936
3	Researching Disability: Overview of the Field	1939
4	Benefits to Research of Co-researcher Involvement	1941
5	Co-researcher Experiences of Inclusive Research	1942
6	Academic Researcher Experiences of Inclusive Research	1944
7	Methodological Issues to Consider When Carrying Out Inclusive Research	1945
7.1	Rigor	1945
7.2	Power and Co-researcher Partnerships	1946
7.3	Training	1946
7.4	Access to Co-researchers	1947
7.5	Co-writing Co-research	1947
8	Conclusion and Future Directions	1949
	References	1949

Abstract

Increasingly academic researchers are becoming involved in inclusive research, in which people with a lived experience of the field of research under study are included as part of the research team. This chapter provides an overview of inclusive research with people with disability. Discussions focus on the dimensions of current inclusive research, including the ethical basis for engagement with co-researchers, and potential barriers and facilitators to successful research. The impact of co-research on both the co-researchers with a disability and academic researchers involved is discussed. Examples of existing projects are provided to give a sense of the field and its limitations and its possibilities.

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Inclusive · Disability · Methods · Rigor · Co-research · Ethics · Consumers

1 Introduction

This chapter focuses on the practice of inclusive research in disability. This approach to research involves the development of research partnerships with the people that would usually be the subjects of research. It is a diverse field of practice and a creative one, with new research approaches being developed to suit the contexts in which the research is taking place. The aim of this chapter is to introduce inclusive disability research and provide an overview of the field by referring to recent inclusive research work. This chapter will describe the dimensions of the field, the issues involved in doing inclusive research, and the benefits of the research both to the project and to *all* the researchers involved.

Why should the “subjects” of research be included as researchers? This question can be answered from a number of different angles, both practical and philosophical. Ethically, or philosophically, the often quoted and important maxim “nothing about us without us” provides a good starting point to think about the ethics of inclusive research (Woelders et al. 2015, p. 529). Many researchers have a strong belief that all research with people with a disability should be emancipatory and include co-researchers as part of this emancipatory project (Björnsdóttir and Svensdóttir 2008; Boland et al. 2008; Woelders et al. 2015).

Practically, “co-researchers” (here I refer to researchers with a disability working with other researchers) are often included because of the different insights that someone with a lived experience of the field of research can bring. They might also be included because it makes it easier to conduct research in a field where some on the research team are known and respected – they thus become gatekeepers to the field. Increasingly, funding bodies are also demanding that researchers include people with a disability in the research process in order for researchers to fulfil their contractual obligations (Case et al. 2014). This means that some researchers may feel forced to include co-researchers, which is not such a great basis upon which to develop a collaborative project. The practical and ethical dimensions of inclusive research will be discussed further later in the chapter

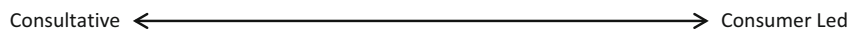
Throughout this chapter, the term “co-researchers” is used to signify those people with a lived experience of disability engaging with research. The term “consumers” is also used to signify people with a lived experience more generally. It is acknowledged that these terms are contested and that in other contexts the terms “service users,” “users,” or “clients” might be used. The term “consumers” is used because that is the most commonly used term in the context in which I teach and research.

2 How Inclusive Is Inclusive Research?

Setting out to define inclusive research is not a straightforward project. This is because the phrase is used to cover a wide range of approaches to research. Inclusive research may variously refer to research that uses co-researchers in an advisory

capacity only, through to research which is led by consumers and all gradations in between. It should also be noted that conversely a wide range of terms is used to cover what is termed here as inclusive research. Frequently used terms include emancipatory research, collaborative research, participatory action research, consumer-led or user-led research, co-research and co-created, and co-developed or co-produced research. These terms are often also used to discuss noninclusive research (e.g., research which merely includes people with a lived experience as participants in the research rather than as researchers), which means that there can be significant difficulties in definition. This should be kept in mind when researching or writing about inclusive research.

Inclusivity is usually characterized according to what extent co-researchers are actually involved in the research. Rose (cited in Horsfall et al. 2007, p. 1202) states that there are three types of co-researcher involvement in research: “consultative, collaborative, and user-led.” “User led” research is that where co-researchers are in control of the whole research project and is positioned in comparison with “collaborative research” which involves a more equal collaboration between co-researchers and other members of the research team (Arthur et al. 2008). Consultative approaches merely use consumers to bounce ideas off. Abma et al. (2009) describe the roles that co-researchers take in research on a hierarchy from “object” of research to “research principal” leading the research. Following this approach, a spectrum of inclusive research can be imagined where at one end sits consultative research (e.g., Lewis et al. 2008) and at the other end sits consumer-led research where co-researchers conceive of and develop the research, directing or employing academic researchers as needed to carry it out.



Consultative ← → Consumer Led

Along this spectrum are positioned other types of research which provide varying degrees of inclusivity. For example, some research may be co-led or be led by academics who then employ co-researchers for a role or number of roles in the project, usually data collection or analysis. Co-researchers are sometimes included in all stages of the research except the project development stage or may be included at just one or two points. Some research includes co-researchers as co-authors in publications, but others do not.

For much research, inclusivity is determined on an ad hoc basis according to project necessities. This can include issues such as funding, co-researcher capabilities and interest, research location, and time limits. An ad hoc approach is viewed as preferable to highly structured models and several authors have reflected on the demands of an ideologically based model and what this meant for both researchers and co-researchers. Nind and Vinha (2014, p. 108) comment that “as a community of researchers, we continue to juggle balancing principles and pragmatics.” Likewise, Woelders et al. (2015, p. 538) feel that inclusive research “can be a rigid concept, guided by the ideal of social justice, expecting the same things of the academic

researcher and the person with intellectual disabilities without a critical look at the added value of including people with intellectual disabilities.” For the researchers in this team, difficulties in implementation of the model necessitated the development of a less structured approach.

In contrast to an ad hoc approach, several structured models of inclusion have been developed and promoted. The most frequently used of these are “inclusive research” (here, confusingly, described as a model rather than a general descriptor) (Bigby and Frawley 2010), participatory action research (Caldwell et al. 2009), collaborative group research (Bigby et al. 2014), and emancipatory research (Björnsdóttir and Svendsdóttir 2008). Each of these models provides a set of principles or structures around the practice of inclusion, which may be useful to some people considering inclusive research. For example, a participatory action research approach sets up principles around the social purpose of research and the extent of inclusion of co-researchers (see also ► Chaps. 110, ““With Us and About Us”: Participatory Methods in Research with “Vulnerable” or Marginalized Groups,” and ► 17, “Community-Based Participatory Action Research”). In relation to disability research, this can be seen in the four principles developed by Selener and Balcazar et al. (cited in Buettgen et al. 2012, pp. 607, 609, 611, 613):

Principle 1. Disabled individuals articulate the problem and participate directly in the process of defining, analyzing and solving it. . . .

Principle 2. Direct involvement of disabled people in the research process facilitates a more accurate and authentic analysis of their social reality. . . .

Principle 3. The process of participatory research can increase awareness among disabled people about their own resources and strengths. . . .

Principle 4. The ultimate goal of the research endeavor is to improve the quality of life for disabled people.

Likewise, the distinct model of inclusive research developed by Walmsley and Johnson (paraphrased in Bigby and Frawley 2010, p. 53) includes the following components:

1. having ownership of research questions;
2. being collaborators; that is, involved in the doing of the work;
3. exercising some control over process and outcomes;
4. being able to access questions, reports and outcomes; and finally
5. that outcomes will further the interests of people with intellectual disability.

As these principles show, many inclusive research projects take an ideological stance to the inclusion of co-researchers. This is most clear in that research described by authors as “emancipatory.” Emancipatory research seeks to actively challenge dominant hierarchies of knowledge, is shaped by a “social model of disability,” and evolves from the disability social movement in the UK (Björnsdóttir and Svendsdóttir 2008). It is underpinned by an explicit social justice framework and is described as a form of “political action” (Woelders et al. 2015, p. 529). The aim is not just to

include or even partner with co-researchers, but to emancipate or free them from a social context which has subjugated them and invalidated their experience in the past. Boland et al. (2008) imply that the term is used too widely and make a distinction between research merely described as emancipatory (research which occurs in *partnership*) and “true emancipatory research” (research *led* by those with a disability). Some researchers have even gone so far as to state that only those people who have a disability should actually carry out research on disability (Björnsdóttir and Svendsdóttir 2008). In projects led by co-researchers, a preexisting group of co-researchers, usually aligned with a service or previous research project, usually devise the research goals and set in motion the project (see Box 2 for example). They then direct the process and are usually involved in each step of the work. However, in a project described by Davidson et al. (2010), the co-researchers engaged academics to carry out the research while they oversaw the research program.

3 Researching Disability: Overview of the Field

The field of inclusive research is mainly restricted to co-research with people with a lived experience of intellectual disability (see Boxes 1 and 2, below for examples) and mental ill-health (see Box 3 for an example).

The vast majority of existing inclusive research focuses on co-research in the fields of health or social sciences and focuses either on service development, consumer experiences of health or social care, and identity (Arthur et al. 2008; Hreinsdóttir and Stefánsdóttir 2010; Buettgen et al. 2012; Hutchinson and Lovell 2013). Most papers also use a qualitative methodology. The most frequently used data collection methods were interviews and focus groups. A small number have used surveys including several with quantitative components (Conder et al. 2011; Kramer et al. 2013; Nicolaidis et al. 2015). Other less-used structured methodologies include randomized controlled trials (Hassouneh et al. 2011) and user-acceptability testing of a computer program (Oschwald et al. 2014). Non-traditional data collection methods are used frequently in inclusive research. This includes visual data collection methods where art is produced by participants (Brookes et al. 2012). Theatre has also been used to collect data via approaches such as “Theatre of the Oppressed” or “Forum Theatre” methods (Daniel et al. 2014). In other projects, existing methods such as focus groups have been refined for use with co-researchers with particular needs. For example, in research conducted by Garcia-Iriarte and colleagues (2009), focus groups were adapted in order to be accessible as a method for collecting data by people with an intellectual disability who found the moderation required in standard focus groups challenging.

These examples demonstrate the creativity of many inclusive research projects which really seek to understand the ways in which co-researchers can best participate in a project to provide meaningful data which will make sense in the organizational and community context in which the results are to be presented. A very significant

proportion of papers that have been published in relation to inclusive research are self-reflexive accounts of inclusive research which do not include a structured methodology but rather provide an account of process and experience.

While an adaptive methodological approach makes sense in relation to the accessibility needs of co-researchers, it can also lead to issues with rigor when compared to other qualitative research projects and existing scales of research quality such as that produced by the National Health and Medical Research Council in Australia or McMaster University in Canada (Letts et al. 2007; NHMRC 2009). A systematic review of inclusive research by Anderson et al. (2015) has emphasized that inclusive research is generally of low quality and that all studies that they included in their review showed research bias. However, one review that has provided a structured comparison of the use of co-researchers in research versus research without co-researchers has found no difference in research outcomes (Nilsen et al. 2013). The quality of inclusive research is discussed further below in relation to rigor.

Box 1 Example of inclusive research including people with a lived experience of intellectual disability

This research has been written up in two papers: Garcia Iriarte et al. (2014) (focuses on research findings) and O'Brien et al. (2014) (focuses on process).

Research aims: To conduct a national study of the experiences of people with an intellectual disability with respect to quality of life.

Co-researchers: People with intellectual disability. The research was directed by a team which included five co-researchers, four researchers, and three assistants. Two of the assistants assisted the work of the co-researchers. Fifteen further co-researchers were engaged in the data collection and analysis.

Methods used: 23 focus groups across Ireland with people with intellectual disability were conducted. Project conducted over a 4-year period. Initial data analysis was conducted by academic researchers and then co-researchers assisted. This happened in a facilitated group event. Separate coding conducted by independent academic researchers to test for validity.

Inclusion: Research topic was developed before co-researchers joined. There was an inclusive advisory group, which provided advice on research in progress. People with intellectual disability on the advisory group needed some time to feel able to speak comfortably. People with a lived experience co-led the research and co-chaired the advisory group. Co-researchers involved in methodology selection, made changes to data collection questions and process (e.g., inclusion of visual prompts), led data collection with support from academic researchers, involved in data analysis (detailed above), helped to develop dissemination strategy, and involved in dissemination and writing of project report.

(continued)

Box 1 (continued)

Impact of co-research on the project: Participants opened up to co-researchers more readily than other researchers. Co-researchers made decisions about data collection which allowed more co-researchers to be involved so that research could take place across the country and be more representative. They were also instrumental in ensuring that the data collection questions were appropriate.

Comments on process: A significant amount of support from local organization was needed for co-researchers to be able to participate, but this was not considered at the start of the project. The quality of this support differed between organizations. Services needed to be better educated about inclusive research to better support co-researchers. Greater clarity was needed of the place of the research assistants in their support of the co-researchers. Meetings were not long enough and needed to be available for telecommuting in order to enable voices to be heard. Training was needed for all researchers. For co-researchers, this involved training in data collection. For other researchers, this involved learning communication strategies for use with co-researchers. Involvement of co-researchers needed to be nurtured. Flexibility of process was important.

4 Benefits to Research of Co-researcher Involvement

In addition to the ethical and emancipatory benefits of inclusive research, there are two main practical benefits of including co-researchers. These were the ability for co-researchers to bring a different type of knowledge into the research process and to act as gatekeepers to a field where academic researchers were outsiders.

Academic researchers often come to a field from either a purely theoretical perspective or with practical experience as practitioners working in the field. What they, therefore, lack is a personal understanding of what it means to receive services or live as someone with a disability. Researchers engaging with co-researchers place value on the tacit knowledge of lived experience and want to enhance the place of that knowledge in their work. While including participants with a lived experience is the traditional way of doing qualitative research, the problem with this traditional approach is that the knowledge of lived experience must be filtered through the academic researcher's lens, which may not focus on what is important or interesting for the participants themselves. Including people with a lived experience as co-researchers helps to ameliorate the subjective bias of the researcher (Abma et al. 2009; Cook and Inglis 2012). Existing literature reveals several ways that co-researcher involvement in a project can help to orient the project towards what is important for people with disability:

1. Participation in the development of project goals so that it is pertinent to the interests of people with a disability and will meet their needs.
2. Involvement in the development of data collection questions, prompts, or stimuli to make sure that they include relevant areas and are phrased in a way that makes sense to the context participants are experiencing.
3. Having a role in data analysis helps to ensure that analysis aligns more with the lived experience of the participants rather than the researcher's detached expectations of that experience.
4. Participation in dissemination and choices about dissemination mean that dissemination is more likely to be done in a way where those whose lives are the subject of the research are able to engage with it.

The other practical reason for including co-researchers is to enable better access to participants (e.g., Abma et al. 2009; Strnadová et al. 2015). Because of a history of poor practices by researchers who have not respectfully engaged with people with a disability when conducting research, there can exist a lack of trust among potential participants. This can make recruitment more difficult and participants reticent to open up to researchers about their experiences. When co-researchers are genuinely included in a project, the inclusion of co-researchers can allow trust to be built in the field because participants can see the respect for consumer knowledge inherent in collaboration (Abma et al. 2009).

5 Co-researcher Experiences of Inclusive Research

One of the biggest challenges with having a mental illness is being invisible. When people look at you, they do not see you. They see your diagnosis. You are constantly over-looked because people think you have nothing to offer your community and society. Sometimes you even overlook yourself as you start to believe what others think of you. Taking part in this project has been a reminder to ourselves and others that we (persons diagnosed with a psychiatric illness) have something important to offer (Case et al. 2014, p. 404)

I am confident and proud of myself. I am a real researcher and this is my story (White and Morgan 2012, p. 102)

Many inclusive researchers include a discussion of how the process of the research impacts on the co-researchers involved (de Wolff 2009; Tuffrey-Wijne and Butler 2010; Cook and Inglis 2012; Williams et al. 2015). This reflexive exercise is important when writing up research as it allows a consideration of co-researcher experiences in relation to their input into the research and its impact on the project outcomes. This needs to be carefully weighed as a project may produce good research, but would be problematic if the process had been overwhelmingly negative for co-researchers. Conversely research may be a good experience for co-researchers, but the quality of research produced is so low that it has little impact. In such a case, the process could be classified as a therapeutic one rather than research. This is discussed further below in relation to rigor.

Co-researchers generally describe their experiences in very positive terms, but are also open about the difficulties of co-research. The positive impact of co-research comes from learning (Abma et al. 2009; Carey et al. 2014), validation and respect (Bigby et al. 2014), connection to others (Bell and Mortimer 2013), work experience (Grayson et al. 2013), remuneration (Case et al. 2014), contributing to the community (Brookes et al. 2012), and the development of personal relationships (Strnadova et al. 2014). For co-researchers, these impacts may result in a changed sense of self, as evidenced in the quotations above, empower them, and have a therapeutic impact (Gillard et al. 2010; Martin 2015; Rome et al. 2015; Tilly 2015).

It is also important to reflect on what might be difficult for co-researchers. While personal accounts of co-research do not tend to speak about the research being overall a negative experience, they do highlight areas of difficulty in their accounts. Co-researchers speak about feeling anxious about the research particularly in the early stages (de Wolff 2009; Case et al. 2014). Others do not understand some of the research or feel comfortable with some parts, such as analysis, and not others (Conder et al. 2011; Strnadová et al. 2015). They also report being upset about aspects of the research including content that is disturbing or makes them recall upsetting experiences (Tuffrey-Wijne and Butler 2010; Hutchinson and Lovell 2013). Some co-researchers also feel uncomfortable about disclosing that they are co-researchers because of community stigma, for example, around mental ill-health (Lincoln et al. 2015).

Accounts of inclusive research show that structured processes core to project progress within universities can also disempower co-researchers. For example, several researchers speak about the problems with ethics processes which question the co-researcher's knowledge and abilities (see Box 3, below and e.g., Flood et al. 2013; Morgan et al. 2014; Walmsley and Central England People First History Project Team 2014). These bureaucratic processes need to be carefully managed so that they do not undermine the confidence of team members.

Box 2 Example of inclusive research led by co-researchers

This research was written up in the paper by Walmsley and Central England People First History Project Team (2014). This article was co-written with co-researchers.

Research aims: The project aimed to create an organizational history of the Central England People First.

Co-researchers: The co-researchers were all people with a lived experience of intellectual disability. They had all been part of the organization which was the focus of the study.

Methods used: Oral history interviews, "talking event" where different perspectives were collected from a group and document and photograph collection. These were used in order to develop a history of the organization.

(continued)

Box 2 (continued)

Inclusion: The project was consumer-led in that all decisions were made by the co-researchers. The inclusion was holistic as described here: “Members of CEPF actively chose to do the project, were in charge of key decisions and carried out much of the work. It was a team approach. Non-disabled people played a hugely significant role, as supporters, advisors and expert consultants – it could not have happened without them – but decisions remained in the hands of the CEPF project team” (Walmsley and Central England People First History Project Team 2014, p. 40). The team employed an academic researcher (Walmsley) to create the history. They also employed a project worker to assist with the project management.

Impact of co-research on the project: The co-researchers enjoyed the project and felt that they produced work of great value. However, they also expressed regret about some of the difficulties encountered. For example, they felt uncomfortable about speaking about or writing up research data about difficult relationships and bullying within the organization’s history so made the decision not to include that information. The project successfully delivered its aims to create a history of the organization. They also produced guides for how to create inclusive oral history research.

Comments on process: Process was hindered by instability in the organization due to staff turnover. Some potential respondents who had left the organization were unwilling to be interviewed by them. They, therefore, got an external person to do the interviews, but this was seen as “not really satisfactory” to the co-researchers who wanted to do all the data collection (p. 38). One of the Universities that they approached were unwilling to include people who are unable to read in research projects so they had to not pursue that research relationship. The project took more time than a project which was not consumer-led. Co-research worked well within this organizational context because they were already co-led by consumers, so this research made sense.

6 Academic Researcher Experiences of Inclusive Research

Several academic researchers have reflected on the process of inclusive research leading to an altered sense of themselves or themselves in relation to academia (Chappell et al. 2014; Kidd and Edwards 2016). This is as a result of researchers questioning their own knowledge or the process of inclusive research engendering a reconceptualization of their values, for example, towards a human rights perspective or as an activist social researcher (following Healy in Stevenson 2010). Gillard and colleagues (2012) write that co-research directly challenges the basis of academic knowledge because it is community driven, elevates nonacademic knowledge, and generally utilizes a nonstandard methodological approach. This can bring those

academics who practice co-research into conflict with their own organizations and put them in a place where they have to justify their “nonscientific” approaches (Kidd and Edwards 2016).

The process of co-research itself can also be practically challenging (Woelders et al. 2015). In Woelders et al. (2015, p. 533), one researcher stated that they felt they “could not live up to the ideals of inclusive research” and that they faced multiple difficulties and challenges in the process. These difficulties can arise from communication problems amongst team members (McClimens 2008) and tension from different timeframes operating in academic versus co-researcher worlds (Dorozenko et al. 2016). This can lead to researchers feeling torn between the requirements of their institutions and their obligations to their research partners. Careful planning in the initial stages of a project and extra time built into the research timeline will help to ameliorate these potential issues.

7 Methodological Issues to Consider When Carrying Out Inclusive Research

7.1 Rigor

The discussion here shows a careful line being drawn between co-research which is rigorous and valid within a wider academic context and that which has important benefits for the co-researchers and their organizations but might lack rigor. As discussed earlier, the research quality of inclusive research papers is generally low. The research methodology and the exact nature of participation of co-researchers are poorly described in many inclusive research studies. For example, a significant proportion of papers state that co-researchers were involved, but do not say how they were involved, what this involvement meant for the research or how this involvement impacted on the co-researchers (Karban et al. 2013; Sherwood-Johnson et al. 2013; Linz et al. 2016). This is a serious limitation of inclusive research studies which has also been highlighted elsewhere (Bigby and Frawley 2010; Jivraj et al. 2014).

The most common methodological relates to uncontrolled and unacknowledged bias. This occurred frequently in papers where co-researchers in the study were also involved as participants and were involved in the project design or data analysis (Ollerton and Horsfall 2013; Azzopardi-Lane and Callus 2015). Critiques of co-research also state that co-research means that the researcher loses objectivity (Kiernan, cited in Tuffrey-Wijne and Butler 2010). Hancock et al. (2012, p. 219) also state that those opposed to consumer involvement cite a “perceived lack of objectivity and capacity and lack of research knowledge/skills.” Some bias may be unavoidable because of the nature of the research, but it is nevertheless important that these issues are acknowledged and spoken about when writing up the research. Failure to do so or clearly think through research before it is embarked upon may mean that the research which co-researchers have put so much time into is not able to be published or change practice because of inherent faults.

7.2 Power and Co-researcher Partnerships

Imbalances of power between the academic researcher and co-researchers can be a significant problem if not explicitly considered in the interactions of a collaborative research project. This results from a history of research practices where the person with a disability has been “studied” rather than genuinely involved. Chappell et al. (2014, p. 386), drawing on the work of Corker and Shakespeare, comment that “the medical model of disability constructs persons with disabilities in terms of ‘deviance, lack and tragedy’ as victims of impairment . . . and as objects to be studied rather than as subjects and agents of research.” Inclusive research challenges this. However, if researchers feel that they are “giving voice” to people with a disability by including them in research, this can also reinforce the problematic medical model – inclusive research has to be genuinely collaborative to meet emancipatory goals. This is a warning against an empty “emancipation” that makes co-researchers feel good but does not move knowledge forward. In order to address these potential problems, academic researchers need to continually employ a self-reflexive approach where they consider their own actions and motivations.

Inclusive research often employs assistants who will help the co-researchers complete data collection or analysis (see for example the research in Box 2). If employing assistants in this way, it should be ensured that the co-researcher “supporters” do not take over or influence the co-researchers (Bigby and Frawley 2010). The danger here is that co-researchers will be co-opted into expressing someone else’s interests rather than their own. The assistants should therefore be trained in research and a set of principles developed for support in order to avoid this outcome (see also ► Chap. 96, “The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research”).

7.3 Training

Inclusive research projects a wide variety of approaches to training, from no training to on-the-job training conducted as needed, and further to highly structured training involving multiple training sessions over an extended period (Northway et al. 2013 and see also Box 4; Strnadova et al. 2014). Training is generally put in place in order to ensure a greater rigor to the data collection project and to help the co-researchers to be confident in their work (Grayson et al. 2013). However, training is not always accepted by co-researchers with Bigby and Frawley (2010) describing one project where co-researchers rejected training and would not engage. On reflection, the academic researchers were positive about this rejection as it made them reconsider the impact of training, which may have been to force co-researchers to fit into an academic mold. For these researchers and others who choose not to train or train more informally, the choice was justified because training might distort the co-researcher’s unique knowledge (Nind et al. 2016).

7.4 Access to Co-researchers

The organizational context in which the research takes place is an important factor in facilitating research progress. In two of the exemplars provided (Boxes 2 and 3), the inclusive research approach worked because the organizational context was already oriented towards collaborative practice. Consumer knowledge was already validated within the organizations, and therefore, the co-researchers were taken seriously and could conduct their elements of the research without having to counter any stigmatized perceptions of their capacity. In other organizational contexts, however, this could be a significant confounder to the research progress (Bart and Abma 2011). Organizational values oriented towards participation make organizational support more likely, assists with co-researcher involvement, and therefore, makes research easier.

In existing inclusive research, co-researchers have generally been physically present to conduct data collection and be otherwise involved in the research. However, this approach significantly limits the participation of co-researchers whose disability may prevent them from co-research in person, including people with certain forms of physical disability or mental ill-health (e.g., social anxiety disorder). Recognizing this limitation, one study including co-researchers with autism developed processes for collaborating online (Nicolaidis et al. 2011). The accessibility of co-researchers should be considered in all inclusive research so that co-research is not just limited to people with the capacity to be physically present to complete research.

7.5 Co-writing Co-research

A significant percentage of peer-reviewed journal articles which write up inclusive research are co-written in some way by people with a lived experience of disability. Co-writing with co-researchers should be considered particularly when they have had a significant part in the design, data collection, or analysis. Inclusion of co-researchers will allow new perspectives and new modes of expression to enter academic discourse. Co-written papers mainly include the co-researchers generally as part of the writing team or by allocating them part of the paper to write from their own perspective (Nicolaidis et al. 2011; Makdisi et al. 2013; Rome et al. 2015). In the consumer-led research reported in Box 2, the co-researchers co-wrote the paper in a style where they took turns with the lead author. Although the project was led by co-researchers, the academic researcher was lead author on the publication (Walmsley and Central England People First History Project Team 2014).

In student projects where co-researchers are part of the research team, student researchers need to ensure that they do enough of the research that it is their own project in order to fulfil the requirements of their qualification (Björnsdóttir and Svensdóttir 2008; Morgan et al. 2014; Dorozenko et al. 2016). The use of co-researchers in student research is another clear example of an ad hoc adaptive approach to inclusion which needs to meet the needs of both academic researchers working within their own world and to meaningfully involve co-researchers.

Box 3 Example of inclusive research in mental health

A self-reflexive account of this research is written up in Case et al. (2014). This article was co-written with the co-researchers.

Research aims: This research aimed to understand the experiences of people with mental ill-health using a particular mental health service. The organization which commissioned the research wanted this qualitative, experiential data to augment existing satisfaction surveys.

Co-researchers: People with a lived experience of mental ill-health. They were people already receiving services through the organization being studied. The co-researchers were employed through a competitive application process and were employed because of commitment to the project goals.

Methods used: 14 focus groups were conducted with 101 people with mental ill-health attending the mental health service. Qualitative analysis of transcripts.

Inclusion: The research derived from interests of an academic researcher and a service provider. Co-researchers were employed in order to carry out the data collection. Co-researchers were given training in research methods over 9 months. Co-researchers facilitated and took notes during the focus groups. An academic researcher also assisted with all focus groups by providing mainly logistical support. Each transcript was analyzed by one co-researcher and one academic researcher. The co-researchers presented the findings. The whole team collaboratively wrote the report.

Impact of co-research: The research effected this desired outcome for the organization of creating organizational change and validating consumer knowledge (see below). The co-researcher input into the language used in the focus groups helped to make the process and questions relevant to the participants. Different types of knowledge were able to be derived from the focus groups when facilitated by co-researchers because the respondents were more forthcoming. The co-researchers contextualized the data through analyzing it within the context of their own lived experience. This provided an insight into the data which were not available to the academic researchers. The collaboration has spawned further inclusive research.

Comments on the process: For the organization, this inclusive research was a natural extension of the collaborative approach taken by the organization. It represented their values of inclusion in practice. It was also a tool for the organization to “elevate the status” of consumers – their inclusion as researchers validated the experiential knowledge they held. Training was provided in an ad hoc fashion where the academic researchers “facilitated” the knowledge of the co-researchers. For the co-researchers, the process was “terrifying” at times (particularly presenting), but overall they felt “valued” and “honored” to be part of the research. They felt that the remuneration was important but also appreciated having something to fill their time.

8 Conclusion and Future Directions

What this chapter aimed to do was to provide an introduction to inclusive research, how it is done, what it means for the people involved, and what to watch out for when creating an inclusive research project. The conclusion aims to suggest how researchers might best put in place initial steps to beginning an inclusive research project. Taken as a whole, this chapter shows there are two essential elements that need to be put in place prior to the research starting: (1) communication and (2) timely preparation.

The first thing needed is to start having conversations with people with a lived experience of disability to find out what is important to them, how a researcher might work in with work that is already being done, or offer skills to groups of consumers who are interested in doing research. From this point, inclusive research will be developed as a collaborative process. Inclusion of co-researchers from the start will help to ameliorate many of the problems identified above and make sure that they are fully included in a project, rather than as an add-on. Their needs are more likely to be considered and their skills used in the best way possible if they are involved from the start.

It is also important to have time to prepare a project over a long period so that issues can be thought through before essential elements such as funding and ethics approval are gained as these processes will usually set in place a methodological approach which is hard to move away from later. While an ad hoc and flexible approach may be the easiest to implement, ad hoc does not equate to a lack of planning. A long lead-time is needed in order to map out, preferably in a collaborative manner with co-researchers, the path ahead, identify potential risks, and develop strategies to mitigate them.

With a focus on choice and control and person-centered care for people with a disability, a central tenet of major policy frameworks in many countries including the UK (e.g., <https://hee.nhs.uk/our-work/person-centred-care>) and Australia (e.g., National Disability Insurance Scheme Act 2013), it is important that those services which are developed meet the needs of people with a disability or choice and control is meaningless. Including people with a disability in the creation of research which evaluates services or develops new practices will be essential to ensuring that practice can be assessed in relation to questions which are relevant to people with a disability. Choice and control is also meaningless if there is no trust in the voice of people with a disability. Inclusive research helps to validate these voices and change practices which have only viewed the experiences of people with a disability through a lens which is not focused on their needs.

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Understanding Sexuality and Disability: Using Interpretive Hermeneutic Phenomenological Approaches 112

Tinashe Dune and Elias Mpofu

Contents

1	Introduction	1954
2	Understanding Sexuality	1955
3	Sexuality and Disability	1956
4	Interpretive and Hermeneutic Phenomenology	1958
5	Interpreting Insider Perspectives	1958
6	Interpretive Hermeneutic Phenomenology Approach Procedures	1959
6.1	Individuals Are Agents	1959
6.2	Hone in on Participant Perspectives	1960
6.3	Participate in the Participants' Daily Life	1961
6.4	Appreciate that the Researched Are also Researchers	1963
7	Trustworthiness Within an Interpretive Hermeneutic Phenomenology Approach	1963
7.1	Step 4a: Assessing Credibility	1964
7.2	Step 4b: Assessing Transferability	1964
7.3	Step 4c and 4d: Assessing Dependability and Confirmability	1966
8	Reflections on IHPA for Our Study and Its Findings	1968
9	Strengths and Limitations to Applying IHPA	1969
10	Conclusion and Future Directions	1970
	References	1971

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Abstract

Disability, and those who live with disability, has been researched widely by scholars across a number of fields. However, there has been relatively little research on how people with cerebral palsy (CP) construct their own sexuality and the importance of the sexual scripts involved in this process. Given that sexuality is a fundamental human right with links to identity, health, and belonging, it is important for researchers in this area to engage deeply with understandings of how people with CP construct, understand, and experience their sexuality. This chapter introduces readers to researching constructions, understandings, and experiences of sexuality by applying an Interpretive Hermeneutic Phenomenological Approach (IHPA) with people with moderate to severe CP. It discusses the rational and processes for applying IHPA to engage participants in these sensitive and complex discussions on their lived experiences of understandings of sexuality. The chapter also provides procedural guidelines for applying IHPA to studying sexuality with CP in addition to the strengths and limitations of this approach. IHPA provides a unique advantage to studying health issues with hidden populations or socially sensitive topics with the general population.

Keywords

Physical disability · Sexuality · Hermeneutic phenomenology · Qualitative methodology · Trustworthiness

1 Introduction

Alex (not real name) and I (Tinashe) were watching television in his relatively accessible, technologically-enhanced and fully mechanized dorm room. As we chatted over the buzzing of the television, our attention was suddenly drawn to a heated and passionate sex scene. The characters had only just met and seemed to be having the best sex of their lives. “Do people really have sex like that?” Alex asked. “I don’t think so. . . No. . . Of course not,” I replied. Alex and I were silenced as both characters simultaneously reached orgasm in a very complicated physical configuration. “Would you want to have sex like that?,” I asked. “You must be joking” Alex replied. Alex, who has severe spastic quadriplegic cerebral palsy, explained to me that sex (for him) was about working with what you had. With a wink, he assured me that no one had ever complained.

Cerebral palsy is neurological condition characterized by poor muscle coordination in carrying out voluntary movements (ataxia), with stiff or tight muscles and exaggerated reflexes (spasticity) which is also associated with muscle tone that is too stiff or with loss of tone (Dune 2011). It also might show with additional symptoms like foot or leg dragging. People with CP tend to have a range of secondary conditions such as seizures, communication and hearing disorders, impaired vision, bladder and bowel control issues, pain and abnormal sensations, as well as mental health conditions such as depression and anxiety (Dune 2011). It affects 1 in 50 live births and presents at birth or soon after with prevalence at around 17 million people globally (Oskoui et al. 2013). With increasing medical support, therefore life

expectancy more people with CP are living well into adulthood globally. Given that CP is becoming a prevalent health condition in adulthood the need to address personal and social care needs in this population including sexuality (Linton and Rueda 2015).

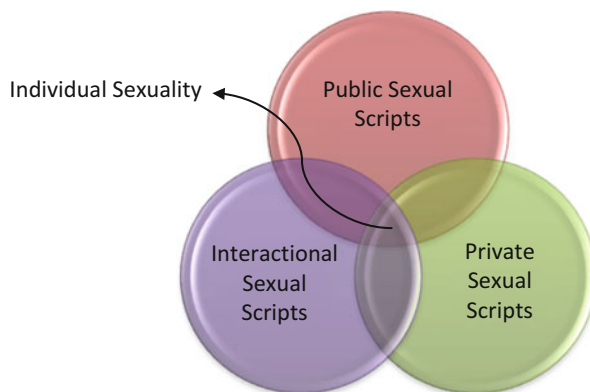
This chapter introduces readers to researching constructions, understandings, and experiences of sexuality by applying an Interpretive Hermeneutic Phenomenological Approach (IHPA) with people with moderate to severe CP. It discusses the rational and processes for applying IHPA to engage participants in these sensitive and complex discussions on their lived experiences of understandings of sexuality. The chapter also provides procedural guidelines for applying IHPA to studying sexuality with CP in addition to the strengths and limitations of this approach. IHPA provides a unique advantage to studying health issues with hidden populations or socially sensitive topics with the general population.

2 Understanding Sexuality

Before researchers can engage with this complex topic with a marginalized population, like people with CP, a deeper understanding of sexuality is required. In order to further appreciate how sexuality may influence the human experience, it is important to note the pathways by which it is constructed. Drawing on theory by Simon and Gagnon (1986, 1987, 2003, 2011), it has been found that human sexuality is constructed via public, interactional, and private sexual scripts. This means that sexuality is expressed in all aspects of human life – what we see in the media, to how we interact with other, to what we see in our dreams.

For example, public sexual scripts are created, influenced, and reinforced by attitudes and interpretations presented in popular culture and media (Dune 2015). We absorb these through consuming and engaging with social media, magazines, movies, or television and the internet. Public events, like cultural or religious events, may impact the expression of sexuality as they expose people to images of what is sexually desirable and/or “appropriate.” As such, people may be encouraged to engage in sexual activity only with those who are publically prescribed as appropriate (Simon and Gagnon 1986). These public scripts then influence the way in which we actually express our sexuality. Based on public scripts, we are influenced to engage in sexual interactions with people who are “sexy” and the media rarely portrays disability as desirable. These interactional events are characterized by the ways in which we negotiate intimate sexual relationships (i.e., flirting, courting, and dating). From these public and interactional scripts and experiences, we develop private inner dialogues about sexuality (Emerson 1983). These private mental processes influence the way individuals internalize sexual scripts and consolidate perceptions and constructions of sexuality – a mental picture of what is sexy, who is sexy, and what we should and should not be – that guides them in their understanding of their sexuality and that of others (Dune and Shuttleworth 2009). In this way, privatizations of sexual expectations, behavior, and constructions are bound to public and interactional social scripts (Dune 2014a). Figure 1

Fig. 1 Influence of public, interactional, and private sexual scripts on the construction of individual sexuality



illustrates that an individual's sexuality (in the center) is therefore a product of public, interactional, i.e., intimate relationships, and private sexual scripts (as presented in Dune and Shuttleworth 2009).

3 Sexuality and Disability

The ways in which people think about disability and sexuality is linked to how it is publically represented (i.e., cultural norms), how people with disability experience interactional encounters (i.e., intimate relationships), and how they perceive of themselves as sexual beings (i.e., sexual self-concept) (Dune 2012a). Given that people with CP are not often present in popular media or represented as being desirable sexual partners, people may internalize the myth that people with CP are not sexual or not sexy enough to engage with (Linton and Rueda 2015). The invisibility of disability is important to expressions of sexuality as individuals may choose potential sexual partners based on their perceptions of what is socially acceptable.

Notably, research indicates that when people with a disability do engage in sexual relations, contradictions between their experiences and internalized scripts of idealized "appropriate" sexual relationships may occur. If social expectations of sexuality are internalized, then sexual difficulties may result. When expectations are not met, people may experience a negative impact on their sexuality. The influence of idealized sexual scripts is important to consider for people with CP because expectations of normative function, bodily movement, and the body beautiful can make access to sexual relationships difficult for many people in this group (Shuttleworth 2000, 2007).

To successfully engage in sexual activity, an intimate understanding of these domains in which sexuality is defined and appropriated is required. This is important to consider as sexuality as normal for people with CP as it is for their typically developing peers. However, there may be fewer opportunities for people with CP to engage with and express their sexuality due to physical and developmental

restrictions which mean that normative movement and functioning is impaired (Dune 2015). For instance, a person with severe spastic CP may find it difficult to gently caress their partner's exposed skin with an open hand therefore changing the way foreplay is assumed to proceed. With little practice comes difficulty in securing opportunities to develop the psychosocial skills required to manage and sustain intimate sexual relationships (Esmail et al. 2010). For instance, being excluded from childhood games like spin-the-bottle or being asked out on a date can result in a limited ability to flirt, approach, consent (or not) potential sexual partners. Individuals, therefore, rely on public, interactional, and private sexual scripts to understanding and expressing their sexuality. However, these understandings and expressions are grounded in the practical realities of opportunity for sexual expression.

Although the consequences of exclusion from sexual opportunities are often perceived of as secondary to other health and medical concerns, being denied this integral aspect of health and well-being can lead to major mental health and physical health issues. As noted, mental concerns include depression, anxiety, and suicidal ideation (Jones et al. 2015). Exclusion from opportunities for sexual development including sexual education can result in people with CP having limited opportunities to practice consent and being susceptible to increased rates of sexually transmitted infections and unwanted pregnancy because of limited knowledge of sexual health and sexual well-being (Alvarelhão and Lopes 2016). Of course, the range of opportunities and/or exclusions exists on a spectrum with some people with severe forms of CP having many sexual opportunities while others with mild to moderate forms of CP having very few. As such, the sexual health and sexual well-being outcomes for a person with CP would logically depend on how opportunities for sexuality are interpreted by the individual in the context of present and evolving social situations. This would include how the individual interprets themselves in the context of public sexual scripts, access to interactional opportunities, and also the person's subjective sense of sexuality and sexual fulfilment.

Sexuality is, therefore, an interpretive experience (Edley 2001; Jackson and Scott 2007). As such, employing a hermeneutic phenomenological approach can assist researchers in gaining a better understanding of how people with CP interpret sexual scripts and construct their sexuality (Heidegger 1962; Husserl 1952, 1980). Research which engages hermeneutic phenomenology is interested in interpretive structures (e.g., sexual scripts and sexual constructions) of experience, how people engage with and understand these experiences in relation to ourselves and others (Ramberg 2008). With its foundations in philosophical studies, hermeneutic phenomenology is useful for examining how public, interactional, and private meanings are deposited and mediated through myth (i.e., myth of sexual spontaneity), religion (i.e., constructions of heterosexuality), art (i.e., erotica), and language (i.e., popular culture and interactional discourse). Ultimately, interpretive hermeneutic phenomenology aims to answer questions about how people interpret the meaning of being, the self and self-identity (Van Manen 2002). The following sections describe this approach and how it can support research related to sexuality with people with disabilities.

4 Interpretive and Hermeneutic Phenomenology

To fully appreciate and begin to understand the role of sexuality in the lives of people with disability, research investigations can benefit from inductively interpreting both the lived experience and the context of the participants and their social interactions (McKiernan and McCarthy 2010). For instance, Koch (1995) emphasized that our cultural and social history informs understandings of one's background or positionality in the world. Interpretive approaches, therefore, conceptualize people's experience as constructed by social and organizational realities (e.g., sexual scripts) (Heracleous 2006). According to Heracleous (2006), interpretive approaches to understanding the human experience acknowledge individuals, in this case research participants with CP, as actors with human agency. Hermeneutic phenomenology also emphasizes the importance of the individual's participation in his or her own creation (Lavery 2003). Heidegger (1962) believed that understanding is a basic form of human existence in that understanding not only helps us know the world, but also makes us the way we are (Polkinghorne 1983). This means that participants are agents who engage in their lives versus simply being along for the ride. This is not to say that life always happens according to their actions or plans but that they, and all people, influence and change their environments and experiences as a result of engaging with them and/or perceiving what those experiences may mean.

In this way, hermeneutic phenomenological inquiry helped to facilitate the aims of the research as it acknowledges that people and the world are indissolubly related through cultural, social, and historical contexts. From this standpoint, the ways in which the participants communicate about their sexuality-related experiences demonstrates how they interpret and shape their own or others' understandings (e.g., the researcher, the researched, sexual partners, friends and family and society) (see also ► Chap. 11, "Hermeneutics: A Boon for Cross-Disciplinary Research").

5 Interpreting Insider Perspectives

Qualitative methodology facilitated the application of interpretive hermeneutic phenomenology as it employs a naturalistic approach to comprehending phenomena in "real world settings [where] the researcher does not attempt to manipulate the phenomenon of interest" (Patton 2002, p. 39). Generally, qualitative methodology is broadly defined as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (Corbin and Strauss 1990, p. 17). Instead, it allows the "phenomenon of interest [to] unfold naturally" (Patton 2002, p. 39) and supports interpretations of insider perspectives (see also ► Chap. 63, "Mind Maps in Qualitative Research").

Insider perspectives refer to individual participant interpretations of a construct or phenomena (Liamputtong 2010; Silverman 2009). An insider perspective allows for the exploration of concepts from the participants own perspective(s). Rich descriptions result from qualitative exploration of insider perspectives (Liamputtong 2010). In turn, rich descriptions allow for interpretative conceptualizations important for comprehensive understandings (Mayoux 2006). In our research, we were able to

engage with these perspective and in-depth descriptions through a series of interviews with participants. This helped us to understand the ways that people with CP construct and experience sexuality in light of normative cultural sexual expectations. The next section describes how we operationalized interpretive hermeneutic phenomenology using qualitative methodology in our research.

6 Interpretive Hermeneutic Phenomenology Approach Procedures

IHPA is a way of engaging in research with marginalized populations that requires researchers to develop projects supported by the following foundational tenets:

1. Individuals are agents
2. Hone in on participant perspectives
3. Participate in the participants' daily life
4. Appreciate that the researched are also researchers

6.1 Individuals Are Agents

This first step acknowledges that individuals, including those in marginalized identities, are agents within their social environments. This does not mean that participants control all aspects of their lives, but that they can and do interpret social phenomena in ways that change the nature of those phenomena. Research with this focus seeks to explore a social phenomenon through this agentic lens where participants' perspectives, voices, and interpretations lead the development of understanding and a conceptual framework for a given social phenomenon. This focus should be reflected in the research objectives and methodologies. In our research, this focus led us to center the perspectives of people with CP with the aim of developing a conceptual model based on their constructions of sexuality. An example of how research objectives and methodology can be used to acknowledge that *individuals are agents* is presented below.

Step 1: Example from <i>Making Sense of Sex with People with Cerebral Palsy</i>	
Research objectives	Research methodology
1. Use IHPA to understand people with cerebral palsy, construct the concept of sexual spontaneity, how they construct their individual sexuality, and what sexual scripts (public, interactional, private) are prioritized within that construction	Qualitative methodology aims to explore phenomena in its nuanced richness was appropriate for understanding <i>insider perspectives</i> of constructions of sexuality by people with cerebral palsy
2. Construct a conceptual model of sexuality which takes into account the interpretive hermeneutic phenomenological experience of people with cerebral palsy	In the context of IHPA, <i>qualitative methodology</i> enables access to social phenomena by prioritizing participants' interpretations of often subconscious experiences and personal learning journeys

6.2 Hone in on Participant Perspectives

The bulk of information available both academically and in popular culture presents a deficit model of disability and highlights the social and sexual limitations experienced by this group. While these limitations and experiences are important to recognize and explore IHPAs, focus on individuals as agents can help researchers to engage with participants' agentic constructions, interpretations, and behaviors. In doing so, researchers can understand more of what people with disabilities, and other marginalized identities, are thinking and doing to understand and manage (where necessary) a range of social phenomena. In our research, this allowed us to develop an in-depth interview guide that allowed participants to bring the researchers into their interpretive processes and behavioral responses to sexuality as they knew it. An example of the questions we piloted with participants demonstrates how data collection processes can *hone in on participant experiences* without focusing on impairment, disability, or deficits.

Step 2: Example from <i>Making Sense of Sex with People with Cerebral Palsy</i>	
Interview guide	Questions/discussion
Introduction	Some people would say that a person's sexuality is made up of a variety of different things. I'd like to ask you a few questions about some of the ways that people think about sex
Grand tour	Tell me about your views about sexuality
	Tell me what comes to mind
	There is no importance to what comes first
	(a) If participant generates concepts, probe concepts (b) If they feel differently ask them why
Private	Generally, sexuality and sexual activities are considered private things. What do you think about that?
	(a) If participant generates concepts, probe concepts
	(b) If they feel differently ask them why
Interactional	When people think about sex, they may often think about having sexual experiences with another person or people. What do you think that means?
	(a) If participant generates concepts, probe concepts
	(b) If they feel differently ask them why
Public	The media presents a lot of information about sex. How do you think that could influence sexuality?
	(a) If participant generates concepts, probe concepts
	(b) If they feel differently ask them why

Using this interview guide the researchers collected data with participants across two or three interactive sessions. The interviews were conducted at a time, place, and format (i.e., face-to-face, telephone, email) of the participant's choosing. During these sessions, the researcher engaged with participants in whatever they were doing at that time (e.g., shopping, eating at a restaurant, relaxing at

home, watching TV, and so on) while simultaneously discussing the interview questions. For some participants who had communication difficulties or became stressed or fatigued, the interviews were extended over more than two sessions. Participants who responded via email participated in two or more sessions in order to allow the researcher to seek (via face-to-face, email, or telephone) clarification if needed. All oral interviews were audio-recorded digitally and then transcribed in full. In line with IHPA, the data were analyzed thematically (see Dune and Mpofu 2015) which provided a clearer picture of participants' daily life and lived experience.

6.3 Participate in the Participants' Daily Life

This can include collecting peer-reviewed and gray literature which describes the experiences of individuals like the participants. Perhaps more importantly, researchers should participate in disability awareness, social, and advocacy events. One does not have to be an advocate in these settings, but should authentically participate in as many social experiences, disability-focused or in the mainstream, related to the ways in which participants experience a range of aspects in their daily life. This should be done before, during, and after the research study. In the present study, this engagement facilitated the development, refinement, piloting, and assessing for trustworthiness (described in Step 4 below), analyzing the data and disseminating the findings in impactful and authentic ways. An example of how researchers can *participate in the participants' daily life* before, during, and after the research is presented below.

Step 3: Example from *Making Sense of Sex with People with Cerebral Palsy*

Engagement	Before	During	After
Academic engagement	Systematized review and analysis of literature on disability and sexuality with particular focus on the public, interactional, and private sexual scripts	Writing on findings from literature review and analysis	Analyzing the findings in line with IHPA
	Exploring CP from medical, historical, and cultural perspectives to better understand how the condition and those who live with it have been constructed	Developing a theoretical perspective around sexual spontaneity with disability	Engaging with literature to compare and contrast the findings
		Piloting of the research with people with CP	Disseminating the findings in academic journals, books, book chapters, and conference presentations

(continued)

Step 3: Example from *Making Sense of Sex with People with Cerebral Palsy*

Engagement	Before	During	After
		Engaging with academic literature to scrutinize IHPA with other methodological frameworks	Cohosting events with people with CP to debate and discuss society's role in sexuality and disability
		Refining IHPA for the main study with people with CP	
		Collecting data in line with IHPA with people with CP	
Social/cultural engagement	Exploring popular and social media to examine content, messages, and constructions of sexuality and disability	<i>Authentically</i> developing friendships with people with disabilities through the research, other friends, social events, online, and employment opportunities	<i>Authentically</i> maintaining friendships with people with disabilities
	<i>Authentically</i> engaging socially with people with disabilities through friends, social events, online, and employment opportunities	Attending social events with research participants during data collection to better understand aspects of their life that they were willing to share	Hosting and participating in mainstream social events (physically and online) related to sexuality
	Participating in mainstream social events (physically and online) related to sexuality (e.g., <i>Sexpo</i>)	Participating in mainstream social events (physically and online) related to sexuality	Hosting and participating in disability-specific social events (physically and online) related to sexuality and disability awareness
	Participating in disability-specific social events (physically and online) related to sexuality and disability awareness (e.g., <i>#deliciouslydisabled</i>)	Participating in disability-specific social events (physically and online) related to sexuality and disability awareness	
Environmental/structural engagement	Trying to understand the lived experience of disability and sexuality through role plays with key informants		
	Spending time in a wheelchair and/or navigating infrastructure without using routes employed by typically bodied people		
	When meeting with a friend, student, or colleague with a disability ensuring that the meeting location is accessible (including eating areas and toilets)		

(continued)

Step 3: Example from *Making Sense of Sex with People with Cerebral Palsy*

Engagement	Before	During	After
Political/ economic engagement	Becoming familiar with the political debates in the area of disability (and sexuality) by attending stakeholder meetings and workshops	Giving participants space to discuss and demonstrate the role of political and economic structures in their lives and sexualities	Using the research findings to support and advocate for changes in portrayals of disability in popular culture, policy, and legislative documents
	Interrogating the role of political and economic structures in the health and well-being of people with disabilities by reading/engaging with policy and legislation		Revising policy documents in line with IHPA outcomes from the research

6.4 Appreciate that the Researched Are also Researchers

Given that participants are agents in their social environments, their role as co-researchers is important to IHPA. This entails allowing participants to contribute to the flow and outcomes of the research. In line with qualitative methodology, this can be done by ensuring the trustworthiness of research and the data emerging from in-depth insider perspectives. Using the current study as an example, the following section will describe how to engage participants towards assessing and ensuring trustworthiness.

7 **Trustworthiness Within an Interpretive Hermeneutic Phenomenology Approach**

As noted in Dune and Mpofu (2015), trustworthiness is a factor which every qualitative researcher should concern themselves with while designing a study, analyzing results, and judging the quality of the study. In qualitative paradigms, the term “trustworthiness” encompasses “credibility,” “transferability,” “dependability,” and “confirmability” (Dune and Mpofu 2015). Credibility is the evaluation of how well the study’s findings represent a sound conceptual interpretation of the data which comes from participant data. Transferability is the potential of the study’s findings to transfer to other settings. Dependability is the assessment of the quality of the collective processes which include data collection, analysis, and theory production. Finally, confirmability is a gauge of the level to which the study’s findings are supported by the collected data. These qualities are important in qualitative inquiry as they affirm the value and utility of one’s research findings (Dune 2011). In assessing trustworthiness, researchers using IHPA can assure readers that the

findings are accurate presentations of participants' interpretive experiences and constructions that are worthy of attention. To assess trustworthiness within our study, we scrutinized the pilot interview guide (described in *Step 2: Hone in on participant experiences*) and processes to ensure they were well aligned with an IHPA. This process as it applies to IHPA is described below.

7.1 Step 4a: Assessing Credibility

Our study was premised upon the assumption that people with CP, in their general understanding of sexuality, would describe it in terms that parallel or mirror private, interactional, and public sexual constructs. As such, a goal of the pilot study was to determine the credibility of these constructs. To tackle the issue of credibility, "member checking" (Liamputtong 2010; Lincoln and Guba 1985) with three key informants was conducted. In the process of member checking, each of the research participants was asked questions via telephone (see Step 2 above) to ascertain whether or not the use of private, interactional, and public conceptualizations of sexuality were credible constructs for this study. In order to ensure interpretive accuracy of the emerging data, both the participants and the researchers identified themes related to sexual scripts within the transcribed interviews. This supported an appreciation of the researched as researchers.

All participants made comments that directly connected private, interactional, and public sexual constructs to one or more personal experiences they had in the past (see Table 1). For example, participants felt that sexuality was made up of many different factors. They further confirmed that while spaces for experiences of sexuality are commonly considered "private" (i.e., in the privacy of one's home or "behind closed doors") the initiation of sexual encounters began in their minds. In addition, participants felt that a satisfactory sex life meant being able to share one's sexuality with others. This included exploring sexual options and activities with different people and settings in order to discover what they really wanted from intimate relationships. Participants also mentioned that they had fantasized about a celebrity or a friend who resembled a media personality when they engaged in sexual activities with themselves and sometimes with others. The participants explained that the media tells people how to deal with sex as well as who and what is sexy. This feedback suggests that private, public, and interactional sexual constructs may be natural to the discourse of people with cerebral palsy in understanding their sexuality.

7.2 Step 4b: Assessing Transferability

Transferability pertains to the potential for a study's findings to transfer to other settings and/or populations. Transferability was achieved as the findings from the pilot study mirror those of similar nature in other studies (McCabe and Taleporos 2003; Taleporos and McCabe 2001, 2002a, b, 2003) which explored constructions of sexuality (i.e., sexual esteem, sexual satisfaction, and sexual ideation) by and within

Table 1 IHPA example of key informant themes related to private, interactional, and public constructs of sexuality

Key informant	Private construct of sexuality	Interactional construct of sexuality	Public construct of sexuality
1	“...sex, like intercourse, isn't something that I'd do with anybody, anywhere. . .I mean, like I'd do it at home. Like, it doesn't have to be in the bedroom or in the bed for that matter but in my own space. . .I'd feel more comfortable”	“Sex is intimate, like not just with yourself, I mean it is in that respect, but I mean like it is connecting. . .connective. . .with someone else. . .Not that having 'sex' with yourself isn't fun or satisfying but doing it with someone else is even better. Like, it reinforces that you are sexy, deserve sex or like you are what or who someone thinks is worthy of 'gettin' jiggy with”	“I mean who doesn't like a good looking body or person. I mean there are so many good looking people, like sometimes it doesn't have anything to do with disability or anything but when they have the features you know? Those things that make someone sexy. . .I mean it's hard I'm sure for anyone to resist that”
2	“I mean look, I don't necessarily 'get it on' on a daily basis, physically I mean, but I don't need that either. . .Look, sometimes it's nice just to think about it, fantasize without anything physical happening. It gets you going, you know?”	“Part of me, my sexuality I mean, is made up of trying, the ability, the desire you know, to try out different things and different people. Like you don't have to have 'sex-sex' but being with different people sensually kind of is like exploring my sexual side. . .figuring it out you know?”	“Jennifer Hawkins, that's right everybody knows who she is. . .But I guess I'm a red-blooded male. Any pretty face that smiles at you. . .Particularly if they're long legged and absolutely gorgeous. You know Donald Trump even seems to think that the sunlight shines out of her every orifice, which it does. And look, to add to the mix, with someone like that, it's really the first time you fall in love although you don't really know it”
3	“I feel like, when I'm having fun, like having sexual type fun with myself or someone else it's just more fun when you think of something or the other person as everything you want. . .why not right? I mean it's my head, I can think of whatever I want”	“The best part of sex, or doing sexy stuff, with other people is the look on their face. I mean like, you know that look when you know someone is having a good time? Like for me, I suspect for everyone that is like the goal, like to please, satisfy the person you're doing sexy stuff with”	“I mean if you have experiences that aren't what people think is right then that can put a damper on things a bit. . .I mean it's ruined by what other people think is supposed to happen for men or women or whatever. . .I mean in that respect things can get confusing because you not doing what 'you're supposed to' even though it makes you happy”

people with cerebral palsy and other physical disabilities. Further, public, interactional, and private constructions of sexuality have been indicated in other relevant research (Shakespeare 1999, 2006, 2013) as salient to experiences of sexuality with disability.

Although this connection was drawn by the researchers, it may be irrelevant if people with CP do not interpret or perceive of the findings in that way. Given that IHPA is concerned with participants' agentic interpretations of sexuality in the context of disability, the key informants (pilot study) and additional participants (main study) were asked if the findings collated by the researchers were in fact transferable to other people with CP that they knew, heard, or read about. All participants agreed that the findings provided a variety of views and experiences related to sexuality they were representative of the experiences of a range of people with CP with varying developmental experiences and/or qualities (Dune 2011, 2012a, 2014a; Dune and Mpofu 2015; Dune 2012b, 2013). Of particular importance to IHPA was participants' affirmation that the findings portrayed people with CP as agents of their own sexuality and sexual experiences. This support of the research's transferability reinforced Steps 1 and 2 of IHPA as described above.

Transferability of this study's protocol was also achieved through making these documents available upon request. While IHPA is focused primarily on participants, a clear description, with examples, of its processes can assist other researchers in their development of IHPA-focused research. As such, providing evidence of the analytic process allows other researchers to repeat, as closely as possible the procedures of this project. In addition, other researchers can utilize IHPA procedures to analyze data from research which explores similar concepts. In this way, transferability can be further accessed and assessed by other research and researchers.

7.3 Step 4c and 4d: Assessing Dependability and Confirmability

Within IHPA, reviewing the dependability of one's research requires assessment of the quality of data collection, analysis, and theory production (Dune and Mpofu 2015). Confirmability relies on dependability and measures the level to which the study's findings are supported by the collected data (Dune and Mpofu 2015). To enhance the dependability and confirmability of the study, an independent audit of the research by a competent peer, familiar with the experiences of sexuality with disability, was completed. This required the independent auditor (who played no part in the study) to review all documents related to the research project, the guidelines and application of IHPA, the study findings, and conclusions (Liamputtong 2013).

The auditor for this project is a practicing occupational therapist with 10 years of experience and has created many training and "how-to" resources to support people with disabilities in enjoying their sexuality. At the time this study was being conducted, she was also conducting research using qualitative research methodologies but had not used hermeneutic phenomenology or the IHPA model developed from our research.

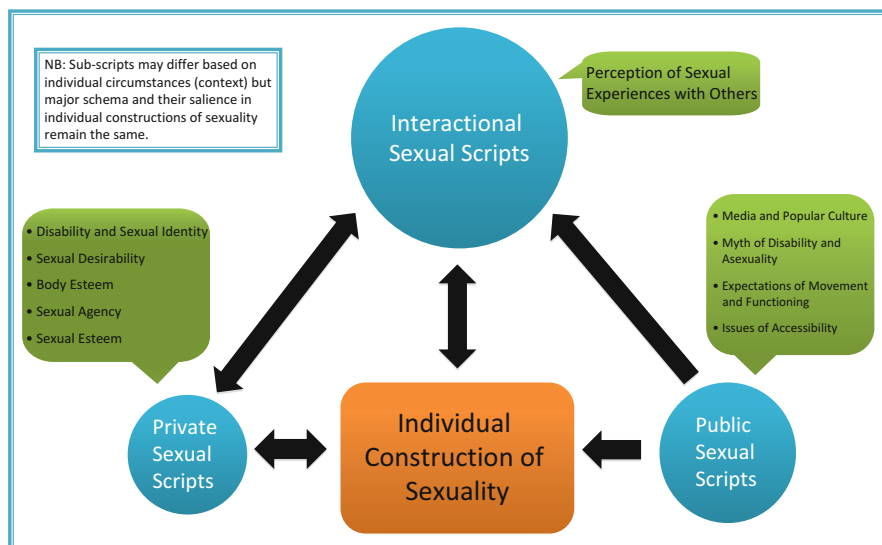


Fig. 2 Model for the construction of individual sexuality in people with cerebral palsy (Dune 2013)

The independent auditor then made an assessment of whether or not the study and its conclusions followed a logical progression through the chain of evidence. Part of this chain may include initial notes on the research question(s), interview schedule, digital audio files, pilot data transcripts, thematic coding and analyses, draft reports and final. To assess the links between the findings and conclusions of the research, the auditor reviewed the emergent conceptual model that depicts the role of public, interactional, and private sexual constructs in the lives of people with CP (see Fig. 2).

The auditors assessment resulted in a written report supporting the links between the research, IHPA, the research findings, and conclusions (full letter available upon request) (Dune and Mpofu 2015). An excerpt of this report is provided below.

Step 4c and 4d: Example from *Making Sense of Sex with People with Cerebral Palsy*

Independent auditor comments

Research design	Data analysis	IHPA related
It is the auditor's opinion that the focus of the study remained consistent with the proposed focus. Ms Dune did, however, slightly reframe her research objectives and questions as it became apparent to her that she was not adequately addressing constructions of sexuality by people with Cerebral Palsy. This revision is to be expected	During the audit meeting with Ms. Dune, I noted the accuracy of the transcription of interviews. I listened to four digital files; two of which were transcribed by Ms. Dune and two which were transcribed by RapidType transcription services. I then noted upon the transcriptions inaccuracies in the text. I listened to at least five pages	It appears that the trustworthiness of the study can be established in that the findings seem to be clearly grounded in the data. The researcher carefully designed her project and employed a number of verification strategies (including the assessment of credibility, transferability, dependability and confirmability) to ensure

(continued)

<p>since qualitative research is an emerging process and initially research questions are tentatively posed. In addition, data collection and verification strategies followed those proposed in the methods section of the proposal. Data analysis procedures slightly changed in that Ms Dune also utilized a manual line-by-line analysis instead of using Nvivo as initially planned. She was also much clearer at the end of the process than at the proposal stage regarding how she approached data analysis. Initially, I had some difficulty making sense of her notes about the evolution of her dissertation included in the audit trail and her manual colored, cut and paste and Nvivo coding system. However, when Ms Dune and I met she walked me through the process and materials pertaining to analysis and specifically outlined the steps she used. The suggestions I made about increasing clarity and brevity within the dissertation were attended to</p>	<p>of each interview (a total of 22 pages) and noted as few as three errors and as many as 20 errors per 5–6 page set. Overall, transcription was exceptionally accurate. The inaccuracies identified were very minor, including single words that were omitted or mistranscribed and/or short phrases that were omitted. In my estimation, the minor inaccuracies did not impact the overall content of the transcriptions</p>	<p>the accuracy of the data. The data were presented in detail in chapter 7 using extensive informants' quotes and descriptive language. Having reviewed all the materials provided to me it appears that the data accurately represents informants' perspectives. The conclusions flow logically from the data presented in results. Comparing those chapters to transcripts, documents, and analytic methods, the conclusions of the study seem warranted</p>
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8 Reflections on IHPA for Our Study and Its Findings

The findings from our research acknowledge that people with CP (and potentially other disabilities) are at risk for stigmatization and exclusion from social activities and sexual participation. This is because normative sexual scripts construct people with disabilities as undesirable and/or asexual (Shuttleworth 2000). This perspective may make it difficult for people with disabilities to fulfil the requirements of normative functioning, hegemonic sexual expectations, and romantic expectations.

The current deficit model of disability often reiterated in academic outlets, and popular media ignores how people with disabilities conceptualize sexuality generally and construct their sexuality specifically. IHPA does, however, acknowledge that sexual expectations and their role in an individual's sexual expressions and activities are intrinsically linked to one's social environment. Even so, our research

highlights that this approach allows researchers and their participants to engage with people with disabilities as sexual beings and agents who construct sexuality through public, interactional, and private scripts. IHPA allowed for both the researchers and the participants to determine which social, sexual, and cultural factors influence individual constructions of sexuality and served as a building block towards understanding sexuality as something humans actively engage with and influence rather than simply being influenced by constructions of it.

9 Strengths and Limitations to Applying IHPA

Employing IHPA to research on sensitive and complex issues, like sexuality, with people with CP supports the role of participants as agents of social phenomena, research processes, and research outcomes. However, there are methodological challenges which researchers should be aware of when attempting to engage people with disabilities using IHPA. These are described and addressed below.

First, IHPA is best applied to marginalized or hidden population. Such populations can be characterized as those “involved in activities that are considered deviant, such as drug taking, or they may be vulnerable, such as the stigmatised in society, making them reluctant to take part in more formalised studies using traditional research methods” (Atkinson and Flint 2001, p. 3). People with CP, or other disabilities, are often considered a hidden population as they are not only stigmatized but may also require daily and intimate care from a range of providers. These providers, like disability support organizations or other carers, may be the first point of contact between people with disabilities and other parts of the community (Dune 2014b). Providers can, therefore, act as gatekeepers who seek to ensure the health, safety, and well-being of people with disabilities (Dune 2015; Shuttleworth et al. 2010). If the gatekeeper deems the research and its objectives to be inappropriate, they may discourage people with disabilities from participating. Simultaneously, it may be the carers or gatekeepers who encourage people with disabilities to participate in research to engage them in the issues and discussions outside of their regular circle of contact (Dune 2011, 2012b). In line with IHPA, it is paramount that researchers develop deep and nonopportunistic trust with gatekeepers, disability organizations, and people with disabilities (Dune 2011). This will assist in developing a collaborative research relationship with participants and opportunities to maximize recruitment capability. Trust can also be developed through snowballing where referrals are made by acquaintances or peers of those who have participated in the research rather than other more formal methods of identification (Dune 2011). As noted in the IHPA procedures, establishing connections with disability networks through piloting of your recruitment strategies and data collection methods can provide important opportunities for member-checking which assists in establishing the trustworthiness of phenomenological qualitative research and the maintenance of participant engagement over the course of the project.

Second, given that some people with disabilities are characterized as existing within hidden populations the trust required for recruitment and data collection may

take the researcher and participant into a gray area of personal and professional space. For instance, when building rapport, the researcher is required to give part of their personal selves within the professional space of the research environment (Emmel et al. 2007). This dissolution of the researcher-participant binary allows the participant to provide robust data and express themselves with little social filtering. Given that IHPA encourages researchers to enter and navigate this gray space, ways for managing these relationships is necessary. As such, this gray space may present issues for both parties when distressing or traumatic experiences are divulged and/or if the researcher-participant relationship ends (Eide and Kahn 2008). In such situations, the line between professional and personal interaction may need to be drawn, bent, or repositioned in order for both parties to process distressing information and/or adapt to the end of the relationship (Robards 2013).

Finally, the analysis and interpretation of qualitative data emerging IHPA for exploring social phenomena with marginalized population should be in line with the principles of trustworthiness. As mentioned, the term “trustworthiness” encompasses “credibility,” “transferability,” “dependability,” and “confirmability.” To ensure credibility, the study’s findings should represent a sound conceptual interpretation of the data which comes from participant data. Transferability is the potential of the study’s findings to transfer to other settings. Dependability is the assessment of the quality of the collective processes which include data collection, analysis, and theory production. Finally, confirmability is a gauge of the level to which the study’s findings are supported by the collected data. These qualities are important in qualitative inquiry as they affirm the value and utility of one’s research findings (Liamputtong 2013). Failure to engage with these principles when using IHPA for qualitative research reduces its rigor and contextual applicability.

10 Conclusion and Future Directions

This chapter discussed IHPA and its application to research on the lived experiences of people with cerebral palsy and their constructions of sexuality. It is a framework which values participants’ perspectives and their agency in both their lives and their ability to articulate and explain their experiences. Given that sexuality is a fundamental human right with links to identity, health, and belonging, it is important for researchers in this area to engage deeply with understandings of how people with disabilities construct, understand, and experience their sexuality. To do this in ways which acknowledge, empower, and value the voices of people with disabilities, better links with this hidden, and stigmatized, population need to be encouraged. Further, sexual and social scripts must be reconstructed to include those who do not seem to meet unattainable expectations. Within this larger call for social change, researchers interested in the lives of people with disabilities should prioritize their voices in the development, engagement, and dissemination of research on their lived experiences – a task which is well supported by an interpretive hermeneutic phenomenological approach.

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Ethics and Practice of Research with People Who Use Drugs

113

Julaine Allan

Contents

1	Introduction	1974
2	Ethical Conduct of Research	1974
3	Recruiting Participants	1975
4	Anonymity	1978
5	Surveys Versus Interviews	1979
6	Intoxication	1981
7	Dealing with Distress	1981
8	Research Participants in Substance Treatment Settings	1983
9	Conclusion and Future Directions	1986
	References	1986

Abstract

Global harm-reduction strategies aim to prevent or reduce the severity of problems associated with nonmedical use of dependence-causing drugs including alcohol. However, harm reduction strategies have to fit the personal, social, and environmental context of people using drugs to be effective. The best way to develop strategies that fit is to research and understand drug use practices including how, why, and when drugs are used. This chapter discusses a number of ethical and practical factors to consider when planning and conducting research with people who use drugs. Data collection challenges include recruitment of a marginalized and hidden population, gaining consent, ensuring anonymity and responding to harm and distress. Examples are drawn from the author's research on alcohol and other drug use in rural Australian settings including farming and fishing workplaces, on illicit fentanyl use, and with people in treatment.

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Drug use · Data collection · Ethics · Intoxication · Harm reduction · Cognitive impairment

1 Introduction

Research on people's nonmedical use of drugs provides vital information for health-care policy and practice. Problem drug use, particularly alcohol, is one of the most significant health-care challenges globally. Alcohol causes 3.3 million deaths annually, 15.3 million people have drug use disorders, and most countries are experiencing increasing deaths from injecting drug use as well as a burden of disease from injecting-related blood borne viruses (World Health Organization 2016).

The principle of harm reduction was proposed by the World Health Organization in 1973 as an alternative to drug control, which had proven unsuccessful in preventing illicit drug use (Ball 2007). The twentieth World Health Organization (WHO) Expert Committee on Drug Dependence defined harm reduction as preventing or reducing the severity of problems associated with the nonmedical use of dependence-producing drugs (WHO 1974). Harm reduction approaches expanded in the 1980s with attempts to control the HIV-AIDS epidemic particularly within injecting drug user populations (Ball 2007). Understanding why, when, how, and what drugs people use is fundamental to developing strategies to reduce harms.

Research with people who use drugs is the best way to develop understanding of their personal, social, cultural, and environmental context so harm reduction strategies can be effectively targeted (Ruefli and Rogers 2004). However, data collection from a stigmatized, possibly vulnerable, and potentially intoxicated population who may be engaged in illegal activity poses practical challenges. Research should be approved by a properly constituted human research ethics committee before commencing but most committees do not provide detailed advice on ways to be ethical. This chapter examines ethical data collection processes and suggests some strategies that can be used to conduct research with people who use drugs.

The ways we understand people's drug use experiences and preferences has shaped the ways drug and alcohol treatment and harm reduction is provided. This is particularly so at Lyndon, the not-for-profit drug treatment, research and training organization conducting the studies described in this chapter.

2 Ethical Conduct of Research

Research ethics aim to safeguard study participants rights by ensuring they understand what they are being asked to do, and what might happen to them as a result of participating in a specific study (Aldridge and Charles 2008; see also ► Chap. 106, "Ethics and Research with Indigenous Peoples"). Typically, the details of a study are set out in an information sheet that is given to a potential participant or details appear

on a screen before information can be collected electronically. Once the study has been explained, people are asked to consent by signing a form, checking a box on a computer screen or by recording their verbal agreement on a digital recorder.

The consent process is straightforward, but the ways you get the information sheet in front of someone assess their capacity to understand it, predict potential harms, and can be challenging. These are the things that have to be explained in an ethics application. For example, in a study examining the impact of different types of heroin on injecting practices, the research team asked for permission to watch the study participant preparing and injecting heroin, recorded the injection on video, interviewed the participant, and then pH tested any drug residue to assess its acidity (Ciccarone and Harris 2015). Numerous ethical issues are highlighted in the research topic and the methods of data collection in the heroin study.

Ethical approval for the study is explained in one of the resulting publications by the following statement;

Approval for this research was obtained by the institutional review boards of both University of California San Francisco and London School of Hygiene and Tropical Medicine. Given the sensitive nature of the research and vulnerability of the participants, a waiver of written informed consent was obtained. Participants verbally consented to each part of the study separately and could refuse any part. No identifiers were obtained so anonymity could be protected. In the US, a Federal Certificate of Confidentiality was obtained from the National Institutes of Health. (Ciccarone and Harris 2015, p. 1104)

The statement indicates the complexity of approval processes across two countries and a number of ethical review groups including the need for some legal protection for the research team in the form of a government certificate of confidentiality that allows them to refuse to disclose participant's names or identifying details to law enforcement authorities (e.g., <https://humansubjects.nih.gov/coc/background>). But, the example does not explain how you might go about conducting research in such confronting circumstances. Practical strategies for participant recruitment, anonymity, state of intoxication, and engagement in treatment or health care are critical to conduct ethical research with people who use drugs.

3 Recruiting Participants

Prior to asking for consent, potential participants fitting the study criteria have to be found. Studies of recreational drug use by young people have recruited participants by setting up booths at music festivals (Lim 2013) and advertising research on social media sites (Butler et al. 2017). Identifying the most likely sites for contact is critical in participant recruitment (see also ► Chap. 5, "Recruitment of Research Participants").

One of the easiest ways to find people who need health care related to drug use is to ask health workers to distribute information about the study or to refer their eligible patients or clients to the researcher. The first challenge to this strategy is health workers perceiving they need to protect people they have a professional

duty of care to. While a reasonable concern, it can also mean the health worker is making a judgment about a person's capacity to participate and/or the relevance of the study.

People in positions of power such as health workers can be effective gatekeepers, preventing research participation because of the ostensibly good motive of protecting someone from harm. Gatekeeping has been a significant barrier to the participation in research with people who have intellectual disabilities (McDonald and Keys 2008; Lotan and Ells 2010), mental illness (Welie and Berghmans 2006), and dementia (Olde Rikkert et al. 1995). The consumer advocacy movement in mental health and some substance use settings has resulted in consumer researchers influencing the ways research is conducted and the consumer's participation in all facets of the research process (Woltmann and Whitley 2010; NAOMI Patients Association and Boyd 2012). However, not all projects include a consumer advocate.

Consumer advocacy is uncommon in Australian drug and alcohol services or for people in community health settings who have problem drug use. In my study of perceptions and experiences of health and health care from socioeconomically disadvantaged rural residents (Allan et al. 2010), the participant recruitment strategy primarily involved distribution of flyers with project information and contact numbers of the researchers in the doctor's practice center, community health center, and drug treatment center in a small rural town. When few people were contacting the researchers, health workers were contacted to ask if they had distributed the information or put up the flyers. We found that health workers were reluctant to pass the information on to potential participants because of concern about the client's fragile mental or emotional state and the harm the research interview could cause. They were also concerned that clients may report a negative picture of the health worker's service delivery.

There were two strategies developed to promote the research project and reduce gatekeeping. The first was meetings with the health workers to discuss the project and answer any questions about potential harms to participants or to the reputation of the health service. It became clear that while health workers were concerned about harm to their patients, in the isolated rural location, they perceived it as likely to be their responsibility to address any distress the research caused. Key information subsequently provided by the researchers included ways that would be responded to by connection to telephone support and others outside of the town. Providing information about how many people had become distressed and required support in previous studies reassured them that it was unlikely but could be managed if it occurred. Describing ways by which the location of the health service and the town would be kept out of publications of the results was critical in allaying concerns about their own or their employer's reputation as a health-care provider.

The second strategy to recruit hard-to-reach participants was the use of snowball sampling or respondent-driven sampling (RDS) (Liamputtong 2007; Gile et al. 2015). Once the flyers for the project were circulated and potential participants began to make contact for interviews, it was much easier to explain the project directly and ask callers if they had any friends or family who met the eligibility criteria. In studies of drug use, snowball sampling is the most effective way to

infiltrate a hidden network of people, many of whom may not use health services or disclose their drug use to a health worker (Gyarmathy et al. 2014; Wohl et al. 2017).

Snowball sampling via a peer network was used to recruit participants in our study of people who injected fentanyl (Allan et al. 2015). Fentanyl is a synthetic opioid with powerful pain killing and tranquillizing properties which is determined to be approximately 100 times stronger than morphine (Lofton and Phillip 2005). Recreational or nonmedical use of fentanyl has contributed to increased overdose deaths in Australia and globally (Hempstead and Yildirim 2014). In some countries, fentanyl is also produced illegally, made into tablets called carfentanil and added to other opioid drugs to increase their potency resulting in a huge increase in overdose and deaths (Middleton et al. 2016).

In Australia, the increase in deaths is related to increased availability of prescription opioids and reduced availability of heroin (Horyniak et al. 2013). A coronial investigation into 136 fentanyl-related overdose deaths recorded between 2000 and 2011 in Australia found that around one-third (34%) were due to fentanyl poisoning, half of the people (54%) had a history of injecting drug use and two-thirds (64%) had not been prescribed the drug that killed them (Roxburgh et al. 2013). Rural areas are over-represented in the overall number of Australian deaths (Allan et al. 2015).

To recruit participants into the study of fentanyl use in rural Australia, flyers were distributed to rural needle and syringe and opioid treatment programs and a residential withdrawal program in three regional centers in rural NSW and Victoria. Recruitment sites included places where people would be actively using fentanyl and treatment centers for those seeking support to stop. Snowball sampling was used to share information about the project through peer networks with flyers including a clear statement of eligibility criteria.

To be eligible to participate in the study, people had to be over 18, speak English, usually reside in a rural location, and have used fentanyl for nonmedical purposes more than once. The flyers included a contact phone number of the researcher conducting the interviews and prospective participants were asked to call for more information and to arrange an interview time if they wanted to proceed. Both men and women were sought for interviews with the aim of achieving 30% female participation to represent the ratio of deaths from fentanyl overdoses, which was 30/70 female to male at the time (Roxburgh et al. 2013).

The flyers and information sheets offered a fifty dollar supermarket voucher for participating in an interview. It was important to explain in the ethics application that the payment reimbursed people for their time and any travel costs but was not enough to be considered an inducement to participate. Concerns about payment to study participants include that money may be used to buy drugs and that people may not want to participate, or be harmed in some way but consent because they want the payment. Researchers have to consider whether a payment somehow influences the representativeness of their sample. Studies into paying people who use drugs or have been in treatment for research participation have found that concerns are mostly unfounded (e.g., Festinger et al. 2008). Payments improve participation and follow-up rates and are typically used by the recipient for essential purchases (Festinger et al. 2008; Dugosh et al. 2014). Further, payment to a study participant is respectful of the time spent and knowledge shared with the researchers (Liamputtong 2007).

4 Anonymity

Ensuring anonymity was paramount in the rural fentanyl study (Allan et al. 2015). Participants were engaged in illegal activity by using and sometimes selling fentanyl for nonmedical purposes. Only two people in the study had been prescribed fentanyl for a medical reason and both described doctor-shopping – attending multiple medical centers reporting made up symptoms – to obtain the drug. Describing how anonymity would be protected, and its limits, was an important first step to gaining verbal consent to participate.

At the first meeting, the research project was explained, and the potential participant was given an information sheet that had more details than the project flyer. Participants had the opportunity to ask questions about the project and have them answered. Possible risks of participation were described by the interviewer, and strategies for dealing with these were discussed. The risks we had anticipated included being identified and linked to illegal activity including drug trafficking, causing harm to themselves or others because of distress caused during the interviews, and risks to children in the care of the participant because of the participant's drug use. Because the research involved describing illegal activity, consent was verbal, no personal information was collected and pseudonyms were allocated to each participant to link demographic details to their interview data. In contrast to the heroin injecting study described earlier, there were no government certificates of confidentiality for the study.

Because there were no legal safeguards to protect anonymity of the participants, the researchers had to explain the limits of anonymity to warn participants when information would have to be passed to authorities. To avoid collecting reportable information, we did not ask direct questions or seek details about crimes. The information sheet included the following statement;

What about my privacy?

Your privacy is assured, and no personal information will be collected. Information about children being abused, threatening to kill yourself or others, and drug trafficking is reportable to the police. We will not ask you questions about those things. We will write a report about what we find out. You will be given a different name in the study report so you cannot be recognized by any person or organization.

The warnings about the limits of anonymity were clear enough for the researchers and participants to be able to discuss drug use practices and experiences without requiring detailed descriptions of people, places, or dates. For example, discussing how they obtained fentanyl, the participants used generalizations and talked about what they believed others to have done without going into details. For example, when talking about procuring fentanyl, participant statements included;

I've always used it through people who've got it themselves. I haven't got it personally, but I know it's easy to get.

Q: How would you usually get a hold of it?

A: Buy it off the street just through dealers that get it wherever they get it from. . .they buy it off other people that are prescribed it, that's what I'm aware of anyway. There's a big market for it, yeah, a big market.

The benefits of the study for people who use drugs were perceived by the research team and the research ethics committee to outweigh the individual risks for participants even though potential harms could be identified (Aldridge and Charles 2008). Participant experiences and explanations were critical to the development of strategies for reducing the risk of overdose death from fentanyl and suggesting ways to disseminate information about health risks associated with fentanyl use. Participants also experienced gains in knowledge and understanding about fentanyl via sharing information during the interview with a researcher with good knowledge of substance treatment. Some sought referrals to drug treatment and health care as a result of the interview. For example, few participants were aware of internet sites that shared harm reduction and user experience information with others;

They just said, “This is how you do it,” and I just done it myself. . . That’s all I’ve heard, yeah. Yeah, that’s all, and these guys have been on it the whole time, so no one has ever told me any different.

The researchers provided study participants with information about useful websites and sources of harm reduction information to ensure that the benefits of the study were not just to the research team in the short term.

5 Surveys Versus Interviews

Anonymity was offered to participants in another project that investigated farming and fishing workers’ use of drugs and alcohol (Allan et al. 2012a). When providing information about the project, the research team explained that participants could choose a pseudonym to disguise their identity if they were concerned about personal information being revealed in any project reports or publications.

Potential key informants were initially identified from telephone books and local newspapers. Key informants were community members with roles in health, primary industries and business, local government representatives, publicans, police and members of civic groups such as the Country Women’s Association. Farm worker and fisher participants were identified through these local industry groups and networks by snowball sampling. A total of 145 farm and fishing workers/contractors, partners of workers, and community leaders across six research sites completed interviews and surveys between November 2010 and May 2011. The farming industry was represented in three sites with a total of 77 participants (53.2%), 46 of whom completed a survey. The fishing industry was represented in three sites with a total of 68 participants (46.8%), 25 of whom completed a survey.

Only two people from 145 participants chose to use a pseudonym for the interviews indicating most participants were either satisfied with assurances of confidentiality or not concerned with being identified in later reports of the study. However, a comparison of the survey and interview results found different types and patterns of drug use between the two data collection methods. In the semistructured interviews we asked;

This project is about drug and alcohol use. Can you tell me about any drugs or alcohol that you use?

The interview prompts included how often, how much, with whom, and when drugs and/or alcohol were used.

In the survey, we used the Alcohol Use Disorders Identification Test [AUDIT] (Saunders et al. 1993), as a measure of self report drinking levels, and the Alcohol, Smoking and Substance Involvement Screening Test [ASSIST] (Humeniak et al. 2010), to identify drug use other than alcohol. We found that many participants reported more illicit drug use and use of more types of drugs in the survey compared to the interviews. For example, one participant stated in his interview;

I don't smoke cigarettes but I've smoked marijuana since I was 18. Yeah, I smoke that flat out as a fucking chicken unfortunately.

He made no reference to other illicit drugs in the interview. However, his survey data reported use of amphetamines, marijuana, cocaine, and ecstasy in the previous 12 months. In another example, two participants reported use of marijuana and amphetamines in the past 12 months in their survey responses, yet in the interviews, both talked about marijuana use in the past;

We were only into pot and a bit of marijuana and beer

Yeah. I used to smoke a bit of marijuana, but found it did no good for me. I wouldn't go out of my way to buy it.

While interviews and surveys have different research approaches and aims, it is likely that some information is easier to reveal in a survey rather than face-to-face in an interview with a stranger. Surveys offer greater anonymity, particularly for collecting sensitive information where a research participant may perceive they will be judged on the basis of their answer if the data collection is face-to-face. The restriction of a survey is the inability to explore reasons for an answer or the person's experience of an event, including drug use (see also ► [Chap. 32, "Traditional Survey and Questionnaire Platforms"](#)).

Technological developments are offering new opportunities for anonymous data collection because technology can mitigate the risk of disclosing sensitive issues (Lee et al. 2003). A project investigating young people's use of drugs and alcohol and their experiences of health-care interventions in relation to substance use is currently being planned. To correctly identify potential participants we will ask questions about their substance use on an iPad during a standardized data collection for the youth health service they are attending. The iPad tool has demonstrated acceptability among young people and when trialed found that young people accessing the service were two to ten times more likely to disclose sensitive issues including substance use (Bradford et al. 2014; Bradford and Rickwood 2015). When planning a study, data collection methods that offer ways of preserving anonymity and easing disclosure of personal information are important considerations for investigating drug use.

6 Intoxication

Assessing a person's degree of intoxication is important when explaining a research project and seeking consent to participate in a face-to-face data collection from people who may have recently used a drug. Being intoxicated affects a person's ability to understand risks or harms arising from participation in research (Donroe and Tetrault 2017). If an individual with no usual communication difficulties cannot talk to the interviewer about the project and ask relevant questions, they should be assumed to be unable to consent. People who are heavily intoxicated will be unable to consent at the time of intoxication but will be able to later even if the effects of the substance are still experienced. It is important for the researcher to have a way of evaluating the impact of intoxication on the person's ability to participate.

Intoxication is best assessed by having a conversation and identifying if the potential participant understands what is being said to and asked of them (Aldridge and Charles 2008). Those who are slurring their speech, sleeping, or stumbling when walking will be assumed to be too intoxicated to participate in research. However, the type of drug causing intoxication will affect the length of time taken for heavy intoxication to wear off. In the fentanyl study prospective participants were asked if they had consumed any fentanyl within the previous 3 h. If they said yes, the interview was delayed until the effects of intoxication had subsided. This took approximately 2 h and could be assessed via pupil size and orientation to day and time. In this example, it is the degree of intoxication that is assessed rather than any state of intoxication limiting participation in the study.

Intoxication is not just a problem for gaining consent. Alcohol affected people can be aggressive and unpredictable causing a risk of harm to the researcher. Intoxication also affects people's responses to interviews or survey questions. Intoxication is frequently implicated in suicide suggesting that people can be in a negative or vulnerable emotional state at the time of intoxication (Arias et al. 2016). Alcohol use in particular is a risk factor in suicide (Currier et al. 2016). Distress related to intoxication needs to be addressed during data collection.

7 Dealing with Distress

Planning ways to respond to distress is important in preparing to conduct research with people who use drugs. A greater proportion of Australians who drink at risky or high risk levels experience high or very high psychological distress (Allan et al. 2012a). In our farming and fishing study, identifying local support services prior to data collection was important because in general rural Australian men have a higher incidence of depression than men living in cities (Currier et al. 2016). They are also more likely than their city counterparts to have experienced a mental disorder associated with substance use throughout their lifetime (AIHW 2010). Furthermore, farmers and farm workers have higher suicide rates than the national male population (Neufeld et al. 2015). Research also indicates that alcohol misuse may be associated with the pressures experienced by farmers as a result of recurrent drought conditions

(Fragar et al. 2011). Asking questions about why farmers and fishers used drugs and alcohol was expected to provoke discussions of problems experienced by research participants in our study.

Harm or discomfort should be anticipated to come from discussions of the problems associated with substance use and the reasons why people use drugs. Participants may become distressed if, for example, they discuss problematic family relationships, trauma, or mental distress. The research interview does not cause the problems and can provide an opportunity for supportive intervention to be offered if required. However, intoxication can make distress worse and people's responses unpredictable as the effects of a drug increase or decrease. For example, the following two quotes from people using fentanyl demonstrate the challenges people face when dependent on a drug:

Opiate users are desperate, and desperate human beings go to desperate measures to seek what they desperately need.

Q: So how many people do you reckon you've seen overdose?

A: Well I know I've seen three or maybe four people in the last 12 or so months, one person twice. I actually had one mate die at just at Christmas time. That was my best mate.

Q: How many people do you reckon you've known have died from using the patches?

A: My missus, two cousins. . . about five of them.

Researchers should be alert to distress expressed by tears, shaky voice, averted gaze, and descriptions of difficulty in daily tasks or relationships with no strategy for dealing with the situation, expressions of hopelessness or helplessness where substance use is concerned, and/or examples of violence or victimization. It is important that interviews are conducted by a researcher experienced in responding to distress and making appropriate referrals when necessary. Participants should be warned in the information sheet and in preparation for the recording of the possibility of the interview causing distress before seeking consent to proceed or delaying the consent and data collection if the person is heavily intoxicated.

Researchers require information and contacts for local and accessible support services when discussing intoxication and drug use with study participants. In the farming and fishing study, interviews raised problems associated with loss and grief;

Ever since he tried to take his own life, he's had so many doubts and so many down days, even that weren't alcohol induced, that I think because – I couldn't manage him; basically I've been his carer. He's an able bodied man, and he's physically fit, but mentally, unfit, unable to make decisions, personally, in his life . . . I have to manage every aspect of his personal life, to a degree.

. . . he went to the boat to sleep intoxicated and fell in the bait tank and died, drowned. Now, that wouldn't have happened if he hadn't been intoxicated.

In these examples, it was important for the researcher to follow-up with questions unrelated to the study; asking the interviewee if they needed support for themselves in relation to the incident or situation they described. The research team ensured that information was left with the interviewee with contact numbers for follow-up, even if they said no to wanting to contact someone for support at the time of the interview.

The research team on the farming and fishing study also developed information for support and advice for research participants who were dealing with intoxication and distress in other ways. For example, a farming employer stated;

Well, we have got a local alcoholic, who did have to have a beer at afternoon tea time, and I didn't sack him because we were desperate but normally if there's any alcohol ingestion during the day, they would be asked to leave or not drink alcohol, or they'd get the boot.

It became clear to the research team early in the study that work place practices were putting employers and employees at risk because intoxication was being ignored;

Question: It's still happening, farm owners allowing guys under the influence to actually work in the farm?

Answer: Yes. It's ignored.

Question: Why do you think it is happening?

Answer: Because they want the hours done, I suppose they don't care because they want the crops off. They'll see the rain and they don't care who comes.

Health-care workers have clear policies and practices for dealing with intoxication in patient presentations, yet still find it challenging (Donroe and Tetrault 2017). In farming and fishing workplaces, there are no guidelines and the additional disadvantage of rural and remote populations experiencing more limited access to prevention, assessment, and treatment compounds the problem (Allan et al. 2012a). In response to the issues raised in early interviews, the research team developed a factsheet with a list of web links to workplace guidelines on recognizing and responding to intoxication and workplace policies on substance use. The factsheet was given to everyone who participated in the study. It was an important research practice to have information available in the short term because the project recommendations that would address the problems raised in the interviews were more than a year away.

8 Research Participants in Substance Treatment Settings

Substance treatment centers offer an easy way to access potential research participants who have used drugs. However, two challenges face the researcher in drawing a sample from treatment centers. The first is ensuring that participants will not perceive their continuing access to treatment or way they are treated by staff is affected by whether they agree to participate in a study, particularly if they have a cognitive impairment. The second challenge is ensuring that data from a sample of people in treatment adequately meet the aims of the study because of loss to follow-up.

People in drug treatment settings are vulnerable because of the circumstances that result in them needing treatment but also because of the unequal power relationship between the treatment provider and the patient or client (Banks 2016). Potential

participants could perceive they are being coerced to join a study. This is particularly the case in residential treatment settings where the withdrawal of treatment could result in increased likelihood of relapse to drug dependence and homelessness. Conducting research in the treatment setting requires a clearly defined assurance that treatment will not be affected by participation or nonparticipation in research. The assurance is usually provided in the information sheet provided to potential participants, but it should also be integrated into the ways data collection is organized and managed.

In our study of the treatment experiences of people with cognitive impairment in a residential substance treatment program, two strategies were employed to assure study participants that the research process was separate to the treatment provided (Collings et al. 2017). Firstly, a project worker gave eligible residents the participant information and consent form and provided a verbal explanation of the research aim and methods. The project worker was not directly involved in the treatment program but visited the program site several times a week to meet potential participants and to conduct cognitive screening with people who had consented to participate in the study. This allowed her to discuss the merits and implications of participation in an impartial way. To address any perceived coercion, the project worker asked eligible individuals to discuss their participation with a family member or friend before deciding to consent or not. The project worker then checked back 2 or 3 days later to find out if the person wanted to participate or not.

The project worker explained to potential participants that participation involved sharing routinely collected individual outcome data using three standardized instruments: cognitive screening results; routinely collected personal demographic information; and the option of taking part in an individual interview when they reached the tenth week of treatment. She also explained how someone could withdraw from participation at any time. All of these meetings and data collection processes were separate from any staff or activities that were part of the treatment program.

Secondly, the researchers remained at arm's length to recruitment by not having any indirect or direct contact with eligible individuals until after they consented to participate. This ensured that the university conducting the research did not exercise any coercive role upon potential participants' decision-making. In reality, the researchers did not contact the participant until just prior to their tenth week in the treatment program which required an additional consent process in reminding people what they had agreed to and asking if they still wished to participate. The preliminary consent was sought shortly after people started in the treatment program and the baseline data collection was being done. This was typically around seven days after entering the program. Nine weeks later, most people had forgotten about the research project and the project worker need to explain again what was required and reminded them what they had consented to. She also explained that they could withdraw their consent if they had changed their minds about participating.

Conducting research with people who had cognitive impairments and used drugs required additional attention to consent processes as described above. However, most research with people who use drugs is highly likely to involve people with

cognitive impairments because of the strong association between substance misuse and cognitive problems. Most substances of dependence impair attention, learning and memory, visual-spatial abilities, and executive functioning (Allan et al. 2012b). Traumatic brain injury (TBI) is also highly prevalent in substance treatment populations, leading to significant complexities in the process of treatment and research with this population (Sacks et al. 2009). If research is to be conducted within a treatment setting, then the prevalence rate of cognitive impairment is likely to be around 50% of the people in treatment (Allan et al. 2012b).

Conducting a number of studies in substance treatment settings raises the potential bias of a sample recruited in treatment. Bias is possible in both the participants' characteristics and their perceptions of substance treatment. This is sometime referred to as the treatment halo effect which is recognized in health-care settings but not specifically in research methods (Kerger et al. 2016). The positive halo refers to those who are most successful in treatment and therefore the easiest to recruit, and also to the descriptions of benefits and impact of treatment by people who are still immersed in the treatment setting and may be overly optimistic about how the treatment will affect them in the future (Holbrook 1983; Baltes and Parker 2000).

Research participants drawn from treatment programs are likely to be those who have the most success with the program in that they are able to adhere to it and find it helpful. It is important to check that those who participate in a study in a treatment setting are not significantly different in age, sex, ethnicity, socioeconomic status, or drug use history from those who decline to participate or who leave treatment early. This is particularly important if the aim of the study is to evaluate the effectiveness or acceptability of the particular treatment (Hser et al. 2004; Zhang et al. 2008). In the study described above of people with cognitive impairment in residential rehabilitation, the project worker spent a significant amount of time contacting people who had consented to participate but left the program prior to the 10 week interview.

In preparing for the study, the high rate of drop out from treatment by people with cognitive impairment was identified as a problem in the final sample of those interviewed and also in the 3 month follow-up rates for substance dependence and well-being measures (Brorson et al. 2013). To minimize the loss to follow-up, the consent forms included participants agreeing to three different ways of contact once they had left treatment. Contact methods listed were the person's own mobile phone including recording multiple numbers if they changed over time; one or two family members or friends telephone numbers and addresses; and contact details of any health or welfare worker that the person had been in regular contact with prior to treatment and who they identified as continuing to support them. Family members, friends, and support workers were sent information about the research so they were aware of the person's consent to participate and that they may be contacted to provide information about the research participant's whereabouts or how to get in touch with them. The follow-up strategy resulted in completion of 12 interviews and eight people agreeing to undertake 3-month follow-up measures from a total of 33 people who initially consented to participate in the study; just under half of whom left the treatment program prior to completion.

9 Conclusion and Future Directions

Substance misuse has been identified as the predominant problem for people who are homeless, experiencing domestic violence or engaged with the criminal justice or child protection systems (Butler et al. 2016). These are all key arenas of work for health and social care workers. However, education and training on ways of working with and addressing substance misuse is a significant gap in professional and practice development in the health and social care sector (van Boekel et al. 2013). For example, strategies for working with substance users have been identified as a key training need of social workers post-graduation (Hall et al. 2000).

Research with people who use drugs is critical to inform and develop health and social care practice to effectively address substance misuse. As a result of research conducted with people who use drugs in rural Australia and those seeking treatment in our programs, Lyndon has developed engagement strategies (Allan and Campbell 2011), peer delivered harm reduction strategies (Allan et al. 2015), assessment and referral pathways (Allan and Kemp 2011, 2014), and a treatment program for people with cognitive impairments (Allan et al. 2012b; Collings et al. 2017).

People report they participate in research because they want to help others and influence policy and practice around drug-related laws and treatment (Barratt et al. 2007). Everyone can use human rights principles to support people's involvement in research and facilitate ways for them to participate as safely as possible (McDonald and Raymaker 2013). Overall, there is an incredible generosity and willingness from study participants to share their experiences, their insights into drug use, and their own harm reduction strategies. It is vitally important for researchers and practitioners to acknowledge study participants' contributions and protect them with practical strategies that are ethical.

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Researching with People with Dementia 114

Jane McKeown

Contents

1	Background	1992
2	Involving People with Dementia Throughout the Research Process	1993
3	Involving People with Dementia as Research Participants	1994
3.1	Recruitment	1994
3.2	Consent	1996
3.3	Research Methods and Approaches	1999
4	Considerations in Involving People with Dementia in Research	2000
5	Methodological Considerations	2001
6	Conclusion and Future Directions	2002
	References	2003

Abstract

Undertaking research with people with dementia has historically been perceived as problematic, especially as the condition advances and where there are concerns over capacity to make decisions and give informed consent. Much research that does include people with dementia as participants tends to focus on people early on in the condition. By not involving people with dementia across the trajectory of the condition, we are failing to develop important understandings from the perspectives of people living with the condition across a range of research topics. Furthermore, by not involving people with dementia throughout the research process, we may not be exploring the most relevant research topics or not considering the most relevant methods and approaches to capture their experiences. There is an increased understanding on the importance of involving people

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with dementia in all aspects of the research process, but the challenge remains on how to do so in a meaningful and ethical way. Researchers are beginning to explore these challenges in the literature. This chapter will draw upon the evidence base as well as personal experience in the UK to consider approaches to consent and a range of diverse approaches and methods that seek to include rather than exclude people living with dementia throughout the research process.

Keywords

Dementia · Research · Involvement · Ethics · Consent · Qualitative

1 Background

Before the 1990s, it was rare to see the inclusion of people with dementia in research accounts and consequently their perspectives tended not to be reported (Hubbard et al. 2003). At that time, research undertaken emphasized a medical model focus on symptoms (Downs 1997), with studies largely focussed on cognitive function and decline (Hubbard et al. 2003). Cottrell and Schultz (1993) suggest that persons with dementia are being described as a “disease entity,” who are seen as unable to share their experience of the condition. Reflecting on the past, a person with dementia notes: “What a hugely missed opportunity it would be if people with Alzheimer’s were excluded from the very thing that could be used to gain a fuller understanding of their disease” (Robinson 2002, p. 104).

The effective exclusion of people with dementia from studies has implications for dementia research specifically (McKeown et al. 2010) but also for research more broadly. Investigations about issues affecting older people more generally will not reflect the specific needs of older people with dementia in their findings if these people are not invited to participate. Taylor et al. (2012) discovered that over a quarter of studies reported in an international geriatric medicine journal over a 2-year period explicitly excluded people with cognitive impairment from participating. Including people with dementia in research will surely improve the quality of research about dementia and about older people.

Since the 1990s, perceptions of dementia have started to broaden and person-centered understandings of dementia have emerged initially from the work of Tom Kitwood (1997). These understandings have contributed to a growing acknowledgment that people with dementia are citizens and have rights, including the right for their experiences to be explored through research (Downs 1997). Interest in psychological and biographical aspects of the life experiences of people with dementia has been important in this change (Hubbard et al. 2003). Increasingly, there is consensus that people with dementia should be included in research as active participants, not purely as subjects (Cottrell and Schultz 1993; Downs 1997; Dewing 2002; Hubbard et al. 2003; Hellstrom et al. 2007). However, challenges in including people with dementia in research remain (Hughes and Castro Romero 2015). This chapter will explore the challenges and offer insights in how such challenges are being overcome.

2 Involving People with Dementia Throughout the Research Process

Involving people in research has in the past been perceived purely as recruiting people as subjects or participants. However, a broader understanding of the ways that people with dementia can be engaged across the research process is emerging.

The framework offered by the National Institute for Health Research (2014, p. 14) identified the aspects of the research process where “patients and public” might take an active role. These opportunities for involvement include: Identifying and prioritizing, design, development of the grant proposal, undertaking and managing, analyzing and interpreting, dissemination, implementation, and monitoring and evaluation. Reports of how researchers have involved people with dementia across the research process remain scarce.

One example of where people with dementia have been involved in the development of research ideas is the UK James Linde Alliance research priority setting exercise. A consensus approach was used with people with dementia, family carers, and others interested in dementia to identify the top ten unanswered questions and dementia research priorities. While such an approach is to be applauded, the process is worthy of closer inspection. Kelly et al. (2015) report that 4.1% of the 1563 completed surveys were known to be from people with dementia, and in the final prioritization exercise, 2 of the 18 people involved had dementia. This reflects the challenges in seeking views of people with dementia in their own right and that the views and opinions of family carers and others can prevail over those of the person with dementia.

The need for public and patient engagement in research as a prerequisite for research funding has led to the formation of dementia-specific research advisory groups. Organizations such as the Alzheimer’s Society offer peer review of research proposals by volunteers. This is a highly valuable process and can provide researchers into insights they may never have considered. However, questions do need to be asked about the constitution of these groups: Is it people with dementia or is it carers who have the dominant voice? Clearly, carers need a voice and their perspectives are essential but more work is required so that people with dementia have their views heard and separated out from those who care for them.

In the UK, groups of people with dementia, for example, the Scottish Dementia Working Group (SWDG), have started to ask these questions. Indeed, this group published core guiding principles for researchers to involve people with dementia in research (SWDG 2014). A network aimed at bringing groups of people with dementia together, known as the Dementia Engagement and Empowerment Project (DEEP), has been formed. A summary of the work of DEEP is reported by Williamson (2012), and the network encompasses over 50 groups. The DEEP network includes groups interested in informing research in a variety of ways. This emerging dementia “activist” movement promises the potential for a different and exciting future landscape for people with dementia in research.

Moving forward, a critical examination of the involvement of people with dementia within the entire research process deserves far more attention. The

remainder of the chapter, however, will explore more specifically the involvement of people with dementia as participants within research studies.

3 Involving People with Dementia as Research Participants

As highlighted at the beginning of the chapter, a number of challenges may arise in the inclusion of people with dementia as research participants. These challenges will be explored through the context of the research process.

3.1 Recruitment

An initial challenge in recruiting people with dementia to research studies is how to access people in order to invite them to join the study. To avoid any suggested coercion by researchers to participate, ethics guidance advises to recruit through “services” or third sector organizations. It is here that researchers may face what Sherratt et al. (2007) term the “gatekeeper challenge.”

Gatekeepers come in many forms and may include care home staff, family members, third sector organizations such as Alzheimer’s Societies, specialist dementia services, and ethics committees. Several layers of gatekeepers may need to be negotiated with in order to access older people with dementia (Hellstrom et al. 2007). While their intentions are usually good, gatekeepers may sometimes be informed by negative assumptions about the ability of people with dementia to speak for themselves. Hughes and Castro Romera (2015, p. 224) report concerns from family carers that the person with dementia “won’t understand,” and consequently, they did not want the researcher to make contact. Witham et al. (2015) explore the challenges of recruiting people with dementia when healthcare professionals identify patients as “vulnerable.” Even with all the necessary ethical and legal permissions on the part of the researchers, healthcare providers may deny access believing research will add an additional “burden” to an already vulnerable individual (Witham et al. 2015). Historically, there has been a practice of paternalism where people with dementia were deemed as needing “protecting,” compared to a more recent change of focus in learning disabilities research with an emphasis on “rights rather than protection” (Hughes and Castro Romera 2015, p. 231).

Such gatekeeping has perhaps withheld opportunities for people with dementia to have participated as fully in all aspects of research (Bartlett and Martin 2002). Equally, it may be that people with dementia “chosen” by services to be advised of research opportunities may not be representative of people with dementia more widely. Published research studies do appear to focus on people in the earlier stages of dementia able to communicate verbally and quite often having support of family carers. It stands to reason that their experiences are likely to be very different from a person with dementia who is more impaired, with communication challenges and living alone for example.

Organizations are developing ways for researchers to more easily make contact with people with dementia. Join Dementia Research in the UK is one such example (see <https://www.joindementiaresearch.nihr.ac.uk/>). Funded by the National Institute for Health Research, the organization maintains a database of people with dementia and family carers who are interested in participating in research. Researchers can then request the details of people who meet their inclusion criteria.

Building and maintaining positive relationships with gatekeepers is essential. It is important that researchers demonstrate their credibility so that they are not perceived to be “using” people with dementia to meet own research needs. Hellstrom et al. (2007) conclude that there are no easy solutions to the gatekeeper dilemma, and researchers must accept that some form of protection is necessary and desirable. King et al. (2016) emphasize that coercion should be avoided and gatekeepers are likely to remain important. It can be the worker at the local Alzheimer’s Society or the Memory Service that is aware when a person with dementia may be overwhelmed by the opportunities for involvement being presented to them. In the broader involvement context, people with dementia themselves identify how tiring such activities can be and that people can feel “over-used” by others who want to involve people with dementia in their work (Litherland 2015).

While accepting that there can be negative personal consequences of involvement for the person with dementia, the potential personal benefits need to also be recognized. Researchers perhaps need to understand and be able to articulate the potential benefits for the person with dementia in participating in research. Data collection can, in itself, be therapeutic for the person with dementia and researchers describe how participants were pleased to be listened to (Barnett 2000; Clarke and Keady 2002). One person with dementia recognized that his experiences of living with dementia may benefit others with the condition (McKillop 2002). A person with dementia I worked with described how participating in forums for sharing his experience made him feel valued as a person and “less like an in-growing toe nail.” People with dementia report that participating in research and contributing to the development of new knowledge can help the person to experience value and positive satisfaction.

In addition to gatekeeper issues, recruiting a diverse range of people living with dementia to research studies appears a challenge. Carmody et al. (2014) identify the additional difficulties in recruiting people from culturally and linguistically diverse communities (see also ► Chaps. 107, “Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds,” and ► 5, “Recruitment of Research Participants”). Researchers have started to recognize the differences in experience that may result from gender, the type of dementia a person has, their sexual orientation, whether they live alone or with family, whether they are physical fit or frail, and whether they live in the community or in a residential facility or are in hospital. The diversity of people with dementia is currently not widely reflected in participants in reported research studies. In their *Call for Change* in research with people with dementia, Carmody et al. (2014) urge researchers to strengthen the

relevance of their research by avoiding the application of overly restrictive exclusion criteria.

3.2 Consent

There can be assumptions by the very nature of a person having a diagnosis of dementia that they are unable to consent. Gaining consent from people with dementia to participate in research is a complex issue. Usual informed consent processes can exclude people with dementia (Dewing 2008). Also, if a person is assessed as unable to consent, there can be assumptions that they cannot take part in the research. These assumptions will be explored in more detail in this section and possible solutions to the challenges discussed.

In England and Wales, the Mental Capacity Act (DH 2005) states that people are deemed capable unless there is evidence to the contrary. The Act (DH 2005) stresses that a diagnosis of dementia does not necessarily mean a person is unable to consent and decisions are situational. If doubts are raised, then the Act asks for a thorough assessment around the following questions: Does the person have impairment of mind or brain? If so, does that impairment mean that the person is unable to make the decision in question at the time it needs to be made? If there are doubts over capacity, then an assessment needs to be made of the person's ability to have: a general understanding of what decision needs to be made and why, a general understanding of the likely consequences of making (or not) the decision, an ability to understand, retain, use, and weigh up the information, and an ability to communicate this.

Maintaining a clear record of conversations and decisions is essential to maintain an audit trail of the consent process. Hughes and Castro Romero (2015) reported comments that participants in their study had made which the researchers perceived to indicate participant understanding of the research they were being invited to take part in. Consent was subsequently recorded verbally on an audio device. To account for the fluctuating nature of consent and challenges for some people with dementia in remembering the previous research conversations, Hughes and Castro Romera (2015) revisited consent upon each research encounter. This process approach to consent is increasingly being reported as good practice when researching with people with dementia.

Dewing (2002) and Hubbard et al. (2003) suggest that a "one-off" act of attaining consent is inadequate for people with dementia, particularly in qualitative research, where consent is viewed as a continual, ongoing process between the researcher and the participant. "One-off" consent process is seen to place the person with dementia in a less powerful position than the person seeking the consent (McCormack 2002). A number of terms have been used to describe ongoing consent. These include: process consent (Usher and Arthur 1998; Reid et al. 2001; Dewing 2002, 2007), ongoing negotiated consent (Crossan and McColgan 1999), and narrative-based approach to consent (McCormack 2002). A framework incorporating key elements of process consent models is proposed by Dewing (2008) where consent is seen as a process running through the entire research project. These elements include:

preparation and background, establishing basis for consent, initial consent, ongoing consent monitoring, and feedback and support. McKeown et al. (2010) report how they utilized this framework within their study on the use of life story work with people with dementia. Researchers may choose to consider this as a pathway to undertaking research with people with dementia in addition to more traditional approaches.

In their review of strategies to maximize the involvement of people with dementia in research, Murphy et al. (2015) propose the CORTE guidelines. Reported in relation to undertaking interviews with people with dementia, the guideline is characterized by attentions to: **C**Onsent, maximizing **R**esponses, **T**elling the story, and **E**nding on a high. **C**Onsent is understood through face-to-face encounters where an importance is placed on getting to know the person. Research assistants were trained to attend to verbal, nonverbal, and behavioral responses of people with dementia during the consent process. Such approaches are thought to reduce people being coerced into research participation. Maximizing **R**esponses necessitates adaptations to the research interview to enable the person to participate as fully as possible. Again, there is an emphasis on getting to know the person and to conduct interviews at a pace, time, and location to suit the individual with dementia. **T**elling the story is a consideration of alternative approaches such as the use of prompts or diaries to help the person share their unique experiences. An important aspect is to enable the voice of the person to be heard as separate from that of their family carer. **E**nding on a high emphasizes the importance of leaving the person with a sense of achievement from the research encounter. This may require building in time after the research interview to spend talking with the person.

As dementia progresses, however, it is accepted that abilities of comprehension, making judgements, reasoning, communicating, and remembering may become increasingly impaired (Hubbard et al. 2002). Thereby, capacity to informed consent may be affected. There is also the possibility that some people may have capacity to consent at the start of a research project but may lose capacity during the project. Some people with dementia have fluctuating levels of capacity to consent. The perceived associated complexity and additional ethical approvals may mean that researchers choose to exclude people with dementia who are assessed as not having capacity to consent. This would appear to be the case as research accounts of people with dementia lacking capacity are scarce.

In the past, proxy consent was often used in place of informed consent from the person with dementia. This approach identified a 'proxy'; most often a relative or close supporter, who knew the person before they developed dementia. This person is then asked, based on the past wishes and values of the person with dementia, to make a decision about whether they should or should not participate. A weakness in this approach is that often the person with dementia and their carer will have different views. The potential for conflict between people with dementia and their proxies has been highlighted by researchers (Sachs et al. 1994; Stocking et al. 2006). Communication with carers of people with dementia suggests that they are often surprised at the choices their relatives make with regard to diet or participation in activities, compared to the past, so it is difficult to ensure that other values

and preferences remain the same with the experience of dementia. Being a proxy decision-maker may prove a burdensome activity for some care givers, and Bartlett and Martin (2002) draw attention to the lack of practical guidance on the best way to involve carers in the process. A further concern regarding the use of a proxy is that the person with dementia is not always meaningfully included in the process as the attention is on the researchers and proxy's responsibilities (Dewing 2002), consequently disempowering a person who has made their own decisions throughout life.

Approaches to the involvement of people lacking capacity to consent vary between nations. It is, therefore, incumbent for researchers to be aware of the ethical frameworks relevant to the country in which the research is to be undertaken. In England and Wales, the Mental Capacity Act (DH 2005) provides clear guidance to researcher on including people with dementia who are not able to consent. Additionally, the British Psychological Society (Dobson 2008) developed further helpful guidance, based on the MCA and the Incapacity Act 2000 in Scotland, to support researchers through the process. Case studies are used to exemplify the process.

When a person is assessed as lacking capacity, the Mental Capacity Act advises the appointment of a "consultee." This person does not "consent" on behalf of their relative; rather, they advise whether they think their relative would want to participate based on past wishes and "best interests." The researcher, however, is obliged to ensure that involvement is in participants' best interests and is in keeping with their wishes. Assent from the person with dementia is required even when the proxy has given consent. Assent is defined as "a verbal agreement to participate based on less than full understanding" (Keyserlingk et al. 1995, p. 340). McKillop, who has dementia (McKillop and Wilkinson 2004), urges researchers to seek permission from the person with dementia before interviewing but believes the involvement of family is important. He suggests differing views to participation between the carer and the person with dementia can be negotiated with the researcher to prevent any confrontation and that "if anything goes wrong they (the carer) are left to pick up the pieces" (p. 119). Similarly, advice from the SWDG (2015) is that researchers should communicate with people who know the person with dementia well. This becomes especially important when there has been a gap between research encounters, to find out whether the circumstances of the person with dementia have changed in any way. Carmody et al. (2014) highlight that there remains no consensus among researchers on the application of assent and dissent in research with people with dementia. Perhaps, a broadening of the debate beyond capacity to consent or not would over time lead to more inclusive engagement of people with a wider range of experience of dementia into research participation.

Dewing (2008) and McCormack (2003) argue that researchers need to present a range of alternative approaches to ethics committees, and consent must move towards methods that fully engage the person lacking in capacity in the research process. Ethical processes do remain challenging for researchers. King et al. (2016, p. 26) report that "stubborn determination" was required to ensure that simplified information sheets remained understandable to people with dementia while also

meeting the needs of the ethics committee. While accepting the need for enhanced ethical procedures, Henwood et al. (2015) draw attention to the strain it can place on research budgets and timescales. Similarly, Holland and Kydd (2015) outline the learning that emerges about ethical issues during the course of a research study and the necessary amendments that may need to be made. As the ethical debate broadens in the literature, then researchers can learn from one other and avoid replicating mistakes.

3.3 Research Methods and Approaches

A further consideration needed in research with people with dementia is the choice of research methods to ensure they are an appropriate approach meaningfully gather the experiences of the participant. This section explores some of the necessary adaptations required to usual methods and identifies the emergence of more creative approaches.

Interviews remain the most reported research data collection with people with dementia. The literature draws attention to the adaptations needed to enable people with dementia to participate in a meaningful way. The development of rapport between the researcher and the person with dementia before the interview is important. This may mean a “preinterview conversation” (Digby et al. 2016) or “chit-chat” (Murphy et al. 2015) on a nonresearch-related topic to convey a genuine interest in the person. This is consistent with the ethical frameworks and guidance discussed earlier in the chapter. A flexible approach to gathering data is preferable to a rigid structure. In reflecting on their research design, Hubbard et al. (2003) concluded that they did not provide the flexibility required to respond to the needs of individual participants. They give the example of how a rigid research protocol prevented them from being able to respond to a participant who was more communicative on a day the researcher happened to be on the ward to see another participant. Flexible approaches are supported by McKillop and Wilkinson (2004), for example, arranging a further visit if a person is becoming tired. It is helpful to establish the “best time of day” for the person with dementia to participate and to avoid noisy environments which can be distracting and make it harder for the person to concentrate. The SWDG (2015) identify the need to feel safe and secure as paramount for any meaningful research activity with people with dementia. Research methods need to instil this sense of security in people with dementia.

The empirical evidence-base to support the use of focus groups as a research method with people with dementia appears to be lacking. Reports from the use of focus groups in service development initiatives identify the method as relevant for people with dementia. A particular reported advantage is the peer support that is offered and that people with dementia can take cues from the responses of others if they lose track of the topic. Again, adaptations are advised. For example, it is best to focus on just one topic for discussion, and it can help if the group is held in an environment that is the focus of the conversation and if people are grouped by topic interest (Bamford and Bruce 2002; Savitch et al. 2006). Bamford and Bruce (2002)

report storytelling by people with dementia as a potential hindrance to gathering data relevant to the research topic. Skilled facilitation is required to enable people to tell their stories while also bringing them back to the research topic and can also help ensure no one person dominates the group discussion (Savitch et al. 2006). Focus groups become more difficult to use with people with more advanced dementia and communication difficulties and with people who find it hard to remain seated for very long (Bamford and Bruce 2002).

Traditional methods of data collection may be less meaningful for people with dementia as their condition advances. It is incumbent on researchers to develop more innovative and creative approaches to enable the views of people with dementia to be heard in research (Alzheimer's Europe 2011). Killick (2001), in discussing how best to gain the views of people with dementia, believes that direct questioning can lead to anxiety and increased confusion. He suggests that time and encouragement is needed to "tease out" their perspectives; he often represents people's views in poetry or narrative. In the context of service evaluation, Murphy (2007) notes that people with dementia can perceive an interview as a "test" and feel under pressure. He urges evaluators to prioritize the relationship with the person over the asking of questions. If discrepancies are evident in a conversation with the person, it is important these are not "thrown in the person's face" but dealt with through sensitive questioning (McKillop and Wilkinson 2004).

Researchers are rising to the challenge and starting to explore alternative approaches to research and or service evaluation with people with dementia. For example, photographic storyboards were used to explore care transitions for people with dementia by Parke et al. (2015). However, their innovative approach to hearing the voice of people with dementia identified challenges as the dementia progressed. Talking Mats© have been advocated as a visual way of seeking the views of people with dementia (Murphy et al. 2010). Bartlett (2012) shares her experience of using video diaries and conversations arising out of other activities, such as walking, hand massage, and singing, have been found to be both enjoyable and providing a promising approach to gaining the views of people with dementia (Allan 2001). Participatory video as a research method is detailed by Ludwin and Capstick (2011). Over the next few years, it is likely that these and other methods will become the subject of empirical examination and do suggest a future where broader range "dementia-specific" research methods can be drawn upon.

4 Considerations in Involving People with Dementia in Research

It was previously suggested that, on the whole, people with dementia do benefit from sharing their views and experiences in research encounters. However, there are some considerations that researchers should be aware of.

Carmody et al. (2014) highlight that some people with dementia may not fully understand the boundaries of research conversations and may share experiences that are more private. This is reported by McKeown et al. (2010), giving the

example of a participant who shared very personal information as part of a research study. In this case, the researchers excluded the personal details from the research study. It could be construed that the person with dementia had lost capacity, but it may be that the relationships formed as part of an inclusive methodology blur the boundaries for some people between a research conversation and a friendly chat. This highlights the responsibilities that researcher need to accept before working with this group of people.

Carmody et al. (2015) identify a further challenge that researchers may become aware of inappropriate carer/partner behavior as part of the research encounter that warrants notification to relevant authorities.

In contrast to the previously reported experience of Bamford and Bruce (2002) of stories being a challenge within focus groups, Digby et al. (2016) describe “tangential stories” as a means for people with dementia to take some control over the research encounter. Such stories are often used if a person is uncertain of what is being asked or what to say. Stories about the past may also be interpreted as reflecting a sense of how the person is feeling in the present (Digby et al. 2016). The challenge for the researcher is to value personal stories and know how to interpret them and sensitively steer the conversation back to the research topic in a respectful way.

Concern has been raised over ensuring that terms used to describe dementia are in keeping with the individual understanding of the person with dementia about their diagnosis. The term “dementia” was not used by Hellstrom et al. (2007) unless it was introduced by the person or their family; the term “memory problem” being used instead. Bartlett and Martin (2002) ask whether fully informed consent is only possible when the person is fully aware of their diagnosis, but concomitantly, appreciating the harm and distress that may be evoked by a researcher unwittingly giving the person a diagnosis. It appears important to meet the participants on their own terms and not insist on them admitting that they have dementia.

5 Methodological Considerations

The choice of methodology is an important consideration for undertaking research with people with dementia. It is suggested that more traditional research paradigms perhaps do not take into consideration some of the more participatory approaches that may be helpful in dementia research (Swarbrick 2015). Ontological and epistemological positions need to be considered and made transparent in methodological choices (see also ► Chap. 6, “Ontology and Epistemology”).

Power is an important issue and involves more than the different status of researchers and the researched, particularly when the factors of age and disability are considered. Furthermore, the different status attributed to health professionals and researchers compared to service users must be acknowledged. It must be questioned whether a nonhierarchical researcher/participant relationship is ever possible or even desirable, and Miller (1998) underlines the dangers of participants

divulging more than they may have wished if they believe the relationship to be reciprocal.

As person-centered practices develop then so too should person-centered research. Such approaches are characterized by a “sustained commitment to participants to ensure the value of the person is held central” (McCormack 2003, p. 182). This especially is relevant for people with dementia and their carers to ensure that they do not feel “used.” Reflecting on the McKillop’s experience as a person with dementia, McKillop and Wilkinson (2004) suggest that if the researcher is not authentic, warm, and genuine, then the person with dementia may pick up on this and be uncomfortable in an interview. Prompting a person-centered approach to research, McCormack (2003) urges researchers to avoid the “hit and run” approach and consider what should be offered to participants following the research. This might be a copy of their recorded interview, sharing findings, ongoing supervision, or training for staff. Participating in research and having their views and experiences heard and valued was perceived by Cowdell (2008) as “nourishing” the personhood of participants with dementia. Such person-centered approaches privilege the needs of the person with dementia over the research encounter itself.

McCormack (2003) argues that person-centered research involves researchers being sensitive and prepared for the variety of unpredictable challenges that may arise in the practice setting. In the prevailing culture of person-centered care and research, perhaps researchers without these skills should not be undertaking such research. An emphatic statement by the SDWG (2014) is that researchers need to have training before being “let loose” with people with dementia. There does need to be an understanding of dementia and sensitivity as to how it affects people on an individual basis (McKeown et al. 2010), certainly if person-centred principles are to be adhered to.

6 Conclusion and Future Directions

The chapter has summarized the range of ways that people with dementia can be “involved” in research more generally, before specifically focussing on the involvement of people with dementia as participants in research studies.

A number of challenges have been identified, ranging from assumptions of others about dementia, ethical and legal aspects along with practical issues to involving people. These challenges, while often there to protect the person with dementia, can result in excluding people from taking part in research. While this is a tragedy for the quality of research, it is also disappointing that people with dementia cannot benefit from feeling valued through sharing their experiences and knowing that they are contributing to a greater understanding of dementia.

Reflecting on the literature over the past 25 years has demonstrated advances, in that people with dementia are participating more in research studies and are viewed far more respectfully than just “disease entities.” This has perhaps benefited research that involves people with dementia with capacity to consent and people in the earlier stages who are able to communicate and participate using conventional research data

collection methods. The next few years may see further advancements in understanding how to best involve people lacking in capacity along with a broader range of data collection approaches to gather experiences in a meaningful way. Ethical processes must continue to protect people with dementia, especially those who may not have capacity to consent, but at the same time must not be so onerous that they deter researchers from including people with dementia in studies.

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Researching with Children

115

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Contents

1	A New Approach in Research with Children	2008
2	Sociopolitical Dimension	2009
3	Cultural Dimension	2010
4	Psychological Dimension	2012
5	Different Methodologies	2013
5.1	Quantitative Methods	2013
5.2	Qualitative Methods	2015
5.3	Mixed Methods	2016
6	Ethics and Research with Children	2016
7	Conclusions and Future Directions	2018
	References	2019

Abstract

Research with children is a vast and complex field, as it is influenced by the conceptions of childhood prevalent in each historical period, each particular culture, and each research team conception. In addition, research with children encompasses different points of view: social, political, cultural, and

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psychological. This chapter provides a review of the current state and the recent developments in each of these fields. Research with children presents researchers with the challenge of finding methods that are well-suited to children and that recognize the importance of children's experience and agency. Such methods should promote a respectful approach based on ethics. We conceive children as the real protagonists, and thus believe they need to be addressed directly. In the same way, children's self-expression, understanding, and empowerment should be promoted through the use of different techniques. For the purposes stated above, this chapter explores the possibility of using quantitative, qualitative, and mixed methods and the emerging of new proposals such as the inclusion of technologies and arts-based methods that present significant future perspectives.

Keywords

Research methods · Children · Sociopolitical · Culture · Psychology · Agency

1 A New Approach in Research with Children

Children represent a particular population group that presents characteristics in relation to the historical time in which they live. They show their perceptions and opinions about reality in a free and creative way. Therefore, to work with them, researchers need to do it in a participative form. This chapter proposes a reflection on research with children from different points of view: social, cultural, psychological, and political, on the basis of different quantitative and qualitative methodologies.

In the 1990s, Qvortrup stated that childhood was a specific and distinct social structure, a permanent social category that is exposed to the same forces that affect adulthood but in a different manner, subject to both paternalism and marginalization. Over the decades that followed such contribution, children's everyday life has been considered to develop in three levels: a material level consisting of the economic, work-related, and technological dimensions; a level of social relations including the family and the community; and a cultural level comprising values and opinions (Gaitán Muñoz 1999).

Childhood, as a social category, has been traditionally defined in a disqualifying manner, as everything that children could not yet be or do, or by comparing their current roles with those they might perform in the future, when they grew up, disregarding what they could do in the present time. In addition, it was a widespread practice in the social sciences to consider children as not competent enough to provide information about their personal and social experiences, as if they were passive observers of the processes they are part of and that take place in their lives (García and Hecht 2009).

Studies concerning children's lives have historically focused on asking adults. In this respect, Hirschfeld (2002) considers that the absence of children as research participants is due to an impoverished view of cultural learning – a view that overestimates the role of adults and underestimates the contribution of children in

cultural reproduction – and to the general disregard for the scope and force of children's culture.

In this chapter, we aim to place children as true protagonists of this study; hence our decision to ask them directly. Thinking about children as protagonists of research implies exceeding the traditional model that is based on the idea that the researcher is the only bearer of knowledge and the person investigated is the passive object that the researcher deals with. It is important to go beyond the idea that boys and girls are the objects of the research and consider them the subjects of it. According to Sen (2000), they are perceived as active agents of change instead of passive recipients of benefits.

This change in the approach of childhood researchers implies a reconfiguration of the researcher-person bond that leads to a new situation according to which both are social and political subjects, bearers of a biographical situation.

Taking into account the theoretical considerations above, the focus of this chapter is to move forward in the perception of children as agents and protagonists. Nowadays, in the research field of social sciences, the condensation and presentation of data on a topic is not sufficient; it is necessary to consider how representations and dialogues have originated and which is the perspective of the social actors (Appadurai 2001).

Research with children presents a challenge that, firstly, leads us to revise our practice as researchers to go on building a scenario that allows the true prominence of the person.

2 Sociopolitical Dimension

We agree with Gaitán Muñoz (1999) that children construct the social reality they live in, transferring experiences to those who will follow them in time, recreating the reality they have been given and developing their own culture. This protagonism strengthens children's abilities and demands, as well as their independent and influential role in society (Liebel 2007).

Children also perform a political role if we define politics according to Rabello de Castro (2007), as the activity that brings people together for them to be able to interpret their own existence and the world that surrounds them. In this sense, politics is understood as a space to build our common sense and collective action. This notion is rooted in Ancient Greece, where interest in children was not for what they were but for what they would become in the future as adults in charge of the *polis* (Kohan 2003). In current societies and according to Kohan (2003), children represent something that is guarded; they are one of the strongest symbols of lack of freedom and power. This is a reason why the subject of emancipation becomes all the more interesting.

The prominence of children and the development of their freedom does not only refer to the autonomy or independence they have, it is also based on their active relationship with the world around them, which is related to the social structure

where they develop their lives and which gives them the possibility of having an active role in society (Liebel 2007).

It is important to point out that “participation implies considering subjects as the protagonists of the decisions; in this way, participation is more than acting together, it is about making decisions together” (Tonon 2012, p. 15). At the same time, the possibilities of participation depend on the nature of social institutions and, in this sense, the State and society play a leading role in terms of responsibility (Sen 2000). The reason for this is that the construction of any democratic society requires the participation of citizens since childhood.

3 Cultural Dimension

From a symbolic perspective, we may define culture as a “universe of senses” (Giménez 2005), and identity as a group of cultural repertoires that have been internalized by social actors, allowing them to differentiate themselves by symbolically creating social frontiers (Giménez 2000). Against this background, studies have been conducted that focus on children in different cultural environments, evidencing the way those environments contribute to creating specificities, that need to be addressed when a research process develops.

Fossheim (2013) sustains that research with children faces different challenges and suggests that there is the need to reflect about three principles: respect, beneficence, and justice of which every culture has different ways to express.

Meanwhile, Boddy (2013) notes that when considering, for example, ethnicity, it should be noted that it covers many different aspects and adds that it is necessary to recognize the intersectionality, i.e., social class, ethnicity, race, sexuality, and gender, while the identity of study participants as children is an element of additional intersection.

In considering this issue, adult research has helped to develop some ethical principles that in his consideration can be extended to studies with children, such as: ensuring given freely fully informed consent and the right to withdraw from research participation.

Other studies analyze the difference between the so-called individualistic and collectivist cultures. Within this framework, Hanson (1992) contends that in individualistic cultures, caregivers encourage children to develop a behavior that will allow them to act independently as early as possible. Kibria (1993), on the other hand, states that in collectivist cultures children are encouraged to ask adults for help instead of solving their problems on their own. Such behavior, according to Kibria, fosters a greater confidence in the other person and, potentially, leads to greater cohesion within the group.

In the context of other studies that consider the cultural specificities of children participating in them, we can mention studies that have reviewed cultural differences among different groups in relation to language. Clark (2000), for example, found socioeconomic differences in parent-child dyads: professional parents tend to talk more to their children than working-class parents and these, in turn, talk more to their

children than parents in poverty. These particularities were strongly connected with the vocabulary used by 3-year-old children.

Hymes (1967), on the other hand, argues that every culture develops its own concept of communicative competence. Moreno (1997), for example, highlighted the differences between American-European and Latin mother-child dyads in connection with the tying of shoelaces. The study focused on questions mothers ask their children aged between 3 and a half and 5: although the questions were similar, generally, American and European mothers asked questions requiring an answer based on the immediate field of perception, while Latin mothers usually made questions about mental representations that were beyond the child's immediate field of perception.

In considering different cultural groups, an obvious reference should be made to children that grow up in bilingual or plurilingual environments. In this respect, different studies (Jackson-Maldonado et al. 1993; Junker and Stockman 2002) have concluded that no delay or particularity in language development was observed in children in bilingual homes. However, Clark (2000), among others, states that it may be very detrimental for a child to learn a language without being able to use it later on because the environment does not present opportunities to put it into practice. Fernandez (2007) refers to different studies that consider that second-language learning contributes to the development of met linguistic awareness (necessary for reading) in that it expands a child's idiomatic experience (Yelland et al. 1993; Liddicoat 2001).

In respect to resources related to cultural sensitivity, Roer-Strier and Rosenthal (2001) state that every parent has an image of their child that guides their childrearing and socialization practices. This image is so fundamental that parents carry it with them even when they immigrate to another context, where it may even limit the child, but it is so deeply held that it is not questioned by the parents.

There are other differences and similarities among different cultural groups. For example, Fu et al. (2007) studied moral understanding in individual and collective-oriented groups from an analysis of truth and lies with children aged 9–11 from Canada and China. This analysis was made through the reading of stories with characters that face moral dilemmas about whether to lie or tell the truth to help a group but harm an individual or vice versa. After reading, the children were required to do certain activities connected to those stories. The major cultural differences lay in choices and moral evaluations. Chinese children chose lying to help a collective but harm an individual, and they rated it less negatively than lying with opposite consequences (they also rated truth telling to help an individual but harm a group less positively than the alternative). Canadian children did the opposite. According to the authors, the major findings obtained were the following: (a) few cross-cultural differences were found in children's categorizations of truths and lies; (b) the cultural environment in which children are socialized plays a significant role in their decisions about whether they might lie and the moral evaluations of lying and truth telling; and (c) there is an interaction between age and children's choices and moral judgments of lying and truth telling (as age increased, Chinese children's choices and moral evaluations increasingly favored the interests of a group over truthfulness and Canadian children became less stringent in their insistence on being truthful and were more inclined to protect the individual). These findings

suggest that enculturation processes may play a relevant role in children's development of moral distinctions between truthful and untruthful communications.

4 Psychological Dimension

The perception of childhood has changed over time and these changes have had an impact on all spheres, including psychology and education. From being seen as unimportant in society, children became kings worthy of unconditional love (Aries 1962), and hold at present an intermediate position in which they receive affection and have limits set on them. They also have rights and responsibilities, interests, needs, concerns, and fears. They are regarded as research participants. The new outlook on childhood recognizes children's potential agency, normalizing them as individuals who take part in research in relation to adults (Christensen and James 2000; Miele Barrera and Tonon 2015).

Research with children in the field of psychology is vast and has undergone different stages. Traditionally, the focus was placed on pathologies, risks, child mortality, use and abuse of substances, violent and risky behavior. These variables were correlated to, for instance, parental styles and family features (Kwan and Ip 2009), cultural differences (Szapocznik and Kurtines 1993; Berry 1997; Lau et al. 2005), socioeconomic variables such as poverty (ECLAC/UNICEF TACRO 2010; Espíndola Advis and Rico 2013; Bornstein and Bradley 2014), and socio-demographic variables such as the level of education (WHO 2012).

The study of salutogenic aspects, such as children's characteristics and possibilities at different stages of their lives, was overlooked for quite a long time. Most common measures of early childhood development pertain to deficiencies in achievements, problem behaviors, and negative circumstances. The absence of problems or failures, however, does not necessarily indicate proper growth and success (Moore et al. 2004; Ben-Arieh 2005). Measures of risk factors or negative behaviors are not the same as measures that gauge the presence of protective factors or positive behaviors (Aber and Jones 1997). In recent years, psychological research has moved from a focus on human distress and psychopathology to happiness, and life satisfaction (Ben-Arieh et al. 2013).

This new theoretical outlook oriented to working on potentialities rather than deficiencies. Thus, placing great value on children's accomplishments, strengths, and values provides a fairer look, and does not pathologize childhood or focus on what children lack in comparison with adults, on what still has not been accomplished.

This paradigm, described as positive psychology or salutogenic approach, has yielded a plethora of research and developments on different aspects. In the field of psychology, well-being is probably the most widely used approach. It has prompted much quantitative and qualitative research, and various instruments have been developed to measure it, with some of them having been used in different languages and countries (Lyubomirsky and Lepper 1999; Ben Arieh 2000).

Extensive research reveals the factors identified by children as central to the development of well-being: love, care, attention, support, security, and the company of their parents; family economic and labor stability; time for playing and sharing with their friends; obtaining high grades at school and taking part in cultural, sports, or artistic activities; having access to technology; not being ill; being satisfied with their physical appearance; experiencing values such as respect, sharing, responsibility, and helping others.

Dissatisfaction is associated with the following: quarrels among parents on issues related to child support, among others; the death of someone close; insecurity, slovenliness, disorder, and traffic problems in the cities where children live; problematic situations undergone by children in the city or bullying; parents' economic and labor difficulties; unfavorable conditions at school, reduced spaces; being unable to participate in community groups or activities; feeling sick (Bradshaw et al. 2007; Míles-Barrera and Tonon 2015).

In addition to well-being, the salutogenic approach also includes other aspects such as happiness, resilience, children's personal life skills such as self-esteem, assertiveness, work capacity, safety, physical status, children's engagement in work, play, social interactions (Lyubomirsky and Lepper 1999; Li et al. 2011; Sanders et al. 2012; Ager 2013; Peterson 2013).

This shift in approach has been fundamental, as it places a growing emphasis on child well-being rather than just on survival, and on enhancing positive outcomes rather than confronting negative impacts, as well as on the voices of children rather than only on adult perspectives (Kamerman 2010).

5 Different Methodologies

The selection of the appropriate research method depends not only on the fact that we are working with children, but also, and fundamentally, on the social, political, cultural, and economic context in which children's lives develop. We, thus, delineate three possible options: the quantitative method, the qualitative method, and mixed methods.

5.1 Quantitative Methods

The field of research with children usually employs quantitative, qualitative, and mixed methods. Each of them presents its own strengths and weaknesses, which must be thoroughly understood for an appropriate selection of methods in each case. The quantitative approach is extensively used for general research purposes and research with children is no exception.

Quantitative methods offer certain advantages, and they prove extremely useful when large samples need to be analyzed, as their level of standardization allows collecting data more easily and quickly, and the results are less prone to researcher

bias (Sampieri et al. 1996; Pita Fernández and Pértegas Díaz 2002; Ben-Arieh 2008; see also ► Chap. 63, “Mind Maps in Qualitative Research”).

One of the advantages of standardized instruments such as indices, surveys, and questionnaires is that they can be used in similar conditions with different populations and contexts. This facilitates comparisons among different groups, cultures, and nations. These methods are important and necessary as they allow obtaining, among others, epidemiologic data and nationwide indices, which will provide a basis for the design of public policies, allocation of resources in social and health areas, and so on (Cook and Reichardt 1986; Sampieri et al. 1996; Binda and Balbastre-Benavent 2013).

Traditionally used in the field of research with children, quantitative research allows comparing groups and obtaining indices, such as poverty and well-being. Standardized instruments are used to compare variations among countries and cultures, and to measure changes over time. Examples of this type of research include: the UNICEF Annual State of the World’s Children Reports; Child well-being Innocenti Report Card; Doing better for children – OECD (Chapple and Richardson 2009).

Today, the use of social indicators is widely accepted and recognized as an important tool in shaping social policies. The questions asked in this connection concern the type and quality of the indicators used. Furthermore, when we do collect data and information on the state of our children the question should be asked: What do we measure and by what means? (Ben Arieh 2000).

Regardless of the research method to be used, the researcher must ask himself or herself what he or she is measuring, whether it is appropriate for his or her culture, and the actual reality of the subjects that participate in the research. It is also critical that the researcher questions the viability of the technique to be used for data collection. Before using indices or questionnaires, the researcher must critically assess the participants’ possibilities of understanding the instrument used, the need for language adaptation, the use of group data collection, the extent of the instrument and its viability taking into account the participants’ age – due consideration should be taken in this respect of the fact that children’s concentration span is more limited than adults’ – and the convenience of implementing other techniques (such as graphs and visual methods) as part of the process (Punch 2002; see also ► Chaps. 116, “Optimizing Interviews with Children and Youth with Disability,” ► 117, “Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization,” ► 102, “Understanding Refugee Children’s Perceptions of Their Well-Being in Australia Using Computer-Assisted Interviews,” ► 99, “Visual Methods in Research with Migrant and Refugee Children and Young People,” and ► 100, “Participatory and Visual Research with Roma Youth”).

One of the major disadvantages of quantitative methods is that, as much focus is placed on large samples and the comparison of populations, the singularity of the participants is usually overlooked. The quantitative approach tends to provide standardized measurements, with the consequent loss of singularity of both the participant(s) and the researcher’s creativity. Therefore, in order to choose the most appropriate method, the researcher should first clearly define the purpose of the research.

5.2 Qualitative Methods

The social reality is constructed through social processes that develop at the same time in a material particular area and other subjective and symbolic. In this context, social actors develop their action within frameworks of certain conditions involving a social world and a natural world, demarcating the borders of their social practices.

The main purpose of using qualitative methods then is to understand the meaning held by the participants regarding the events, situations, and actions in which they are involved, the context in which they act and its influence on their actions, and the process in which actions take place, which at the same time enable the identification and generation of new theoretical understanding about the lives of the participants (Maxwell 1996; Liangputtong 2013; Bryman 2016; see also ► Chap. 63, “Mind Maps in Qualitative Research”).

It should likewise be considered that the qualitative approach implies gaining access to the world of the research participants (in this case, children), and involves a report on their cognitive and emotional aspects (Gilbert 2000), which inevitably brings up this topic from the very start, not to mention that any particularly sensitive question regarding the participants’ accounts may not only be touching to them but also to the researchers. Moreover, Collins and Cooper (2014) focus on emotional intelligence, regarding it as “a capacity for recognizing our own feelings and those in others for the purpose of motivating and managing our relationships and ourselves” and, considering the complexities of human interaction as well as the complexities of research work – which resorts to interaction as a data collection method – they further point out that emotional intelligence is an innovative alternative to the learning and development of qualitative research techniques. Furthermore, they believe that the emotional intelligence framework includes two main areas: (a) personal competence and (b) social competence, which respectively apply to self-management and social awareness, thus enhancing qualitative research with a more flexible role and, subsequently, more interesting findings.

Considering specifically children, Rodriguez Pascual (2006) notes that there has been a finding that the assumptions about the social life of children underestimated their ability to function as active social agents, interpreting and influencing social situations. This has had both theoretical and methodological effects and although he alludes to sociology, we think it can be considered in general.

For that reason, even if today, we can say that children have been constituted as study subjects per se, they realize their own experiences with their own voices, they are subjects of study from a present dimension and not only as future adults, and all this occurs in the context of the characterization of childhood as a structural and cultural component of societies (James and Prout 1997; Rodriguez Pascual, 2006), we have to remember what Fuhs (1999) points out about the fact that adults occupy a status that is established on the basis of an asymmetrical relationship that children know. That is, in research with children, intergenerational axis is key, with different scopes in research (for example, research is controlled by adults).

5.3 Mixed Methods

When we make reference to mixed research methods, we should clarify that such methods must be distinguished from methodological triangulation or collaboration.

Triangulation was defined by Denzin (1978) as the combination of methodologies for the study of the same phenomena or process. However, in practice, this approach has been dominated by quantitative methods to the detriment of qualitative ones, and it is difficult to find studies which give both methods an equally important weight.

According to Coffey and Atkinson (1996, p. 19), the combination or juxtaposition of different research techniques does not reduce the complexity of our understanding, given that the more we examine our data from different viewpoints, the more we can reveal – or, in fact, construct – about its subjectivity.

The mixed methods approach is a type of research in which the researcher or team of researchers combines qualitative and quantitative elements in order to gain depth of understanding and corroboration (Johnson et al. 2007; see also ► Chaps. 4, “The Nature of Mixed Methods Research,” and ► 40, “The Use of Mixed Methods in Research”).

In the case of research with children, the use of mixed methods allows the researcher to understand in a deeper sense what children are thinking and feeling. For example, in an analysis of the quality of life of children it is interesting to use a mixed methods approach in which the use of quantitative methods and qualitative methods can facilitate the comprehension of the opinions children have about their own quality of life, instead of asking the adults about the children’s opinions.

The decision of using mixed methods are considered to be an approach to knowledge that integrates theory and practice from multiple viewpoints, perspectives, positions, and standpoints both on a qualitative and quantitative basis (Johnson et al. 2007). In this way, the importance of the use of mixed methods resides in the first question that leads the research project (Tonon 2015).

When we refer to mixed methods research, we need to explain that we do not understand those methods to be the sum of the results obtained from the use of quantitative and qualitative methods. Rather, mixed methods result in an integration, which is greater than the mere sum of them and allows the construction of a new identity.

6 Ethics and Research with Children

Research with children poses a series of ethical challenges that concern us both in our capacity as researchers and as individuals (see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”). In this respect, Fossheim (2013) identifies three basic principles: respect for the persons, doing good (on the part of the researcher), and justice. All these, in addition to the evident complexities of the researcher’s personal reflections, highlight the awareness of the working context as

critical to assess such notions from the perspective of the participants. That is to say, not only is knowledge coconstructed, but also a “field of interaction,” which modulates the different ethical approaches in the respect to the different, the learning process, and the reaction of surprise/amazement (i.e., how should written informed consent be handled in certain contexts where the main weight of culture is oral?). Thus, research with children, on children, their views, perceptions, emotions, ideas, and so on calls for a larger contribution, that of the exercise of real interaction with the recognition of children as subjects of law.

Researchers must approach children with curiosity, attention, sensitivity and simplicity, and above all, with the conviction that children have a lot to say. There is no one more qualified than them to speak about what they are like, what happens to them, and what they need.

Against this background, any cleavages of power present in the study must be thoroughly identified and analyzed. This implies an assessment of the researcher’s principles and context (i.e., are such principles relevant to the rules of ethical research proposed in the context of the researcher’s residence and in the context in which the research is being conducted?) as well as the scope of the relationship with children – a matter generally discussed in the context of qualitative research. In other words, an ethical, dialogical, and flexible space must be created on the basis of the ethics of interaction. As discussed by Abebe (2009, p. 463, cited by Kjørholt 2013):

[Ethics] entails a moral consideration grounded in respect for local, gendered and socio-spatial constructions of childhood, as well as the need to go beyond acknowledging such complexities to ask how moral and ethical spaces are (re) produced and who they actually serve.

Besides that, Boddy (2013) points out that there are discussions of research ethics, especially when considering children, between protection and participation. On this issue, Powell et al. (2011) sustain that there is no essential conflict between the right to have a voice and the right to be protected but it is a question of balance.

In recent decades, there can be identified various ways of working with children in research. One of them is the one that reflects the traditional research model with an asymmetrical power relationship between researchers and researched. In this way of involving children in research, the researcher is attributed expert status and we can talk about “research on children.” Another way is that in which the research is still directed by adult researchers but involving children in some or all parts of the research. We talk then about “research with children.” Another way is the one of “research by children,” in which children initiate, develop, analyze, and disseminate research (with the necessary skills to do that, of course, having being taught on them) (Backe-Hansen 2013).

In any case, we ought to carry on with our research work, providing critical considerations on new conceptual and methodological contributions in a context of a dynamics of power derived from the identities engaged in dialogue; paying special attention to temporality and spatiality – the support variables of any social relation – with firm belief that the production of knowledge is not external to social construction; and, above all, privileging human relationships.

7 Conclusions and Future Directions

Children represent a particular population group that presents characteristics in relation to the historical time in which they live. They show their perceptions and opinions about reality in a free and creative way; therefore, to work with them, researchers need to do it in a participative form (See also ► [Chap. 116, “Optimizing Interviews with Children and Youth with Disability,”](#) and ► [117, “Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization”](#)).

Research with children must take account of the sociopolitical, cultural, and psychological dimensions. This is so given that “[i]n working with children, we are gaining access not only to their knowledge and subjective experiences, but also to the whole complex of their culture, family life, beliefs, and the social collective imaginary” (Glokner Fagetti 2007, p.75). From a political standpoint, we agree with Kohan (2003, p. 279) who argues that “those who deny children the ability to think do so because they have previously created an authoritarian and hierarchical image of thought, an image that excludes that which will be then branded as incapable.”

With respect to children’s different cultural contexts, we can state that such contexts seem to contribute to the creation of specificities that translate into life experiences in different spheres (Hanson 1992; Edwards 2005; Fu et al. 2007). Along the same lines, we argue that in recent years, psychology has moved away from the classical focus on children’s pathologies and risks towards more salutogenic aspects (Ben-Arieh et al. 2013; Peterson 2013).

With respect to the methodological aspects, significant developments have taken place in recent years that have led to new perspectives. This chapter provided an analysis of quantitative and qualitative methods and explored the relevance of using mixed methods. Mention should also be made of new emerging proposals – such as the inclusion of technologies and arts-based methods – that present significant future perspectives. The inclusion of technologies such as the internet and the use of email – as is the case with email-based surveys – facilitates, among others, large-scale surveys (Scott 2000). In addition, image-making technologies – providing children with digital video cameras, participative video – (Cochran-Smith and Lytle 2011) and other technology-supported creative productions such as blogs bring the researcher closer to the language and forms of expression used by children and young people.

Another significant line of research is provided by the arts-based methods: the self-portrait, graphic elicitation, mapping, timelines (Bagnoli 2009; Boydell et al. 2012). These methods present the advantage of allowing the researcher to come closer to children, as the use of visual and graphic language – which children find more comfortable – provides them with empowerment and a sense of agency (Bagnoli 2009). Children often feel more confident in creating drawings, photographs, and videos than words. Additionally, children’s visual culture is central in childhood studies (Prosser and Burke 2008). These methods enable the adult researcher to gain insight into the children’s world, while at the same time respect their language and capture different experiences. They are also comprehensive, offer

a variety of choices, and can be used at different stages of the research. They open up future lines that can lead to new perspectives, which should not lose sight of the ethical aspects and the role of children as agents.

All of the above considerations lead to the conclusion that our theoretical-methodological approach to research on, for, and with children will be guided by the way in which we perceive children. In this sense, we view children as protagonists. This challenges us to reflect on our research practices, the creation of ethical spaces, and who they are really useful for. The reason for this is that we understand the production of knowledge to be part of the construction of society, and underscore once again the nonneutrality of the knowledge thus produced and the researcher's commitment to his or her work.

It is likely that many researchers will involve children in their research. We hope that what we have discussed in this chapter will provide some theoretical standpoints that researchers can adopt in their research with children around the globe.

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Optimizing Interviews with Children and Youth with Disability

116

Gail Teachman

Contents

1	Introduction	2024
2	Framing Research with Children	2025
3	Assembling Multiple Customizable Interview Methods	2026
3.1	Setting the Stage	2026
3.2	Role Play with Character Dolls or Puppets	2028
3.3	Cartoon Captioning	2030
3.4	Photo-Elicitation	2032
3.5	Vignettes	2033
3.6	Sentence Starters	2034
4	Partnering with Parents	2035
5	Child–Researcher Power Relations	2036
6	Conclusion and Future Directions	2038
	References	2038

Abstract

While there is a growing body of literature explicitly outlining methods for interview studies with children, few have focused on engaging children with disabilities. This chapter describes innovative techniques, strategies, and methods for engaging disabled children and youth in qualitative interviews. A child interview methodological approach is described with an emphasis on three key elements: assembling a range of customizable interview methods; partnering with parents; and consideration of the power differential inherent in child–researcher

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interactions. Drawn from the author's research, examples are used to illustrate the methods and discuss how they were adjusted as the research unfolded. The methods and strategies discussed in the chapter might equally inform interview research with participants of all ages and abilities.

Keywords

Child · Disability · Interviews · Qualitative research · Youth

1 Introduction

Researchers undertaking interviews with disabled children might ask: Is there a need for specialized methods? How can existing methods be adapted to support participation of disabled children in the research process generally, and in interviews specifically? If time constraints limit a child's participation in research to a single interview, how can data generation be optimized? This chapter addresses these questions and outlines an innovative methodological approach to combining techniques, strategies, and methods for optimizing interviews conducted with disabled children and youth (see also Teachman and Gibson 2013). A note on terminology: acknowledging debate on the matter, the term "disabled child" and other variants are used in line with critical disability scholarship which emphasizes that disability is not an individual trait. Rather, it is produced through social relations (Barnes 1995; Morris 2001).

Many articles and books have focused on the process of engaging children in interviews (e.g., Docherty and Sandelowski 1999; Morrow 2001; Kortessluoma et al. 2003; Christensen 2004; Irwin and Johnson 2005; Kirk 2007; Christensen and James 2008; Danby et al. 2011). Most often, the methods described involve multiple interviews or prolonged engagement with children in participatory ethnographic designs. Some exemplary work is available to guide studies involving more extended engagement in children's health contexts (Drew et al. 2010; MacDonald et al. 2011; Nicholas et al. 2011). These relatively intensive methods are generally desirable to produce in-depth, situated data. However, researchers might design studies involving single interviews with child participants in a variety of circumstances; for example, when there are limits on the time available with participants and their families, when multiple interviews might create an unreasonable economic burden for families, or when access to participants is limited by distance.

Children with disabilities accumulate a great deal of expertise specific to growing up with impairments and through early immersion in the worlds of medicine, rehabilitation, and special education. Their perspectives are vital to informing understandings of the impact of these institutions and services on the lives of disabled people. Research that involves a single child interview can sometimes be more readily accommodated by parents of disabled children because of the time constraints and busy schedules their families typically experience. Less information is available to guide single interview methods with children and youth with disabilities.

Following a brief review of principles framing research with children, the chapter highlights three key elements of a methodological approach for doing

research with disabled children. These include: (a) assembling multiple, readily adaptable interview methods; (b) partnering with parents prior to interviews; and (c) reflexive consideration of the power relations inherent in child–researcher interactions. Empirical examples are used to illustrate the methods (see Box 1 below). The potential benefits and limitations of these approaches are discussed, along with description of the iterative process involved in modifying and adapting interviewing methods as research unfolds. The methods described in this chapter could be applied in many types of research, but will be particularly useful in studies where opportunities to become familiar with child participants prior to an interview are limited, and where data generation is limited to one or two interviews.

Box 1 Study Context

All the examples described in this chapter are drawn from a study conducted in Ontario, Canada, that explored the beliefs, assumptions, and experiences of disabled children, their parents, and clinicians regarding the importance of walking (Gibson et al. 2012; Gibson and Teachman 2012). The study was framed within a critical social science perspective (Eakin et al. 1996) with explicit intentions to explore ways that dominant normative discourses about walking are reproduced, reformulated, and resisted, and to (re)consider taken-for-granted assumptions in the field of children’s rehabilitation. Six pairs of participants (each pair consisted of a child or youth with cerebral palsy and one of his or her parents) were interviewed for a total of 12 study participants. The children and youth who participated were between 7 and 18 years of age. All had been involved in some type of walking therapy and used an assistive device (e.g., walker, wheelchair) for at least some of their mobility needs. Separate one-on-one interviews with parents and their children were conducted in participants’ homes in all but one instance. The study will be referred to as “the walk study” throughout this chapter.

2 Framing Research with Children

In research that is informed by the *new social studies of childhood*, children are positioned as active, competent, and expert research participants whose perspectives on issues that affect their daily lives in the here and now are important and likely to differ from those of their parents (James and Prout 1997; Christensen 2004; see also “Research with Children & Participant-Generated Visual Timelines with Street-Involved Youth Who Have Experienced Violent Victimization”). This view contrasts with previously dominant approaches wherein children were viewed as adults-in-the-making, incapable of understanding and sharing their own experiences. Those views suggested that children’s lives should be understood and interpreted through a more “mature” adult lens. Shifts in how childhood and children are conceptualized have challenged researchers to reconsider taken-for-granted assumptions inherent in many methods developed specifically for children (Christensen and Prout 2002;

Punch 2002; Christensen 2004; Irwin and Johnson 2005; Kirk 2007). For example, Christensen (2004) noted a weakening of conventional research approaches in which researchers do things “to” children, and a move toward researchers researching “with” children. The approach challenges the assumption that special methods are needed for research, that a different set of ethical standards is required, or that the problems faced during research process are unique to working with children (p. 165). It has been argued, for example, that novel techniques for use in qualitative research with children might be equally helpful when interviewing adults (Punch 2002; Kirk 2007). Many visual and arts-based methods described in research with children were originally developed and continue to evolve in research with adults (Miles 1990; Catterall and Ibbotson 2000).

This chapter is aligned with childhood scholars who recommend that research practices be reflective of individual children’s experiences, interests, values, and routines, and that researchers consider the unique ways that children routinely express and represent themselves (Punch 2002; Kortessluoma et al. 2003; Christensen 2004). This recommendation is particularly relevant when undertaking research with disabled children where planning and adaptation might be necessary to align the research methods with each participant’s abilities, preferences, and communication styles. In what follows, three key elements of methodological approach used in research with disabled children are illustrated with examples drawn from the author’s research.

3 Assembling Multiple Customizable Interview Methods

3.1 Setting the Stage

It can be helpful to begin a child interview by introducing an activity that helps to set the stage. This type of activity can help set up the interview as a discussion rather than a more formal exchange of questions and answers, and establish there are no “right” answers. This type of activity is often referred to as a “warm-up.” In the walk study, an “interviewer card game” was incorporated. The activity was similar to a method termed “talking cards” by Moore et al. (2008), who reported it was highly rated by child participants when they were asked to reflect on interview methods that they would recommend. In the walk study, the method was used to: (a) increase comfort and reduce anxiety on the part of participants; (b) aid the interviewer in gauging the communication style of the participant; (c) diminish the power differentials by giving explicit permission for the child to question the interviewer and by reinforcing that there were no “right” answers; and (d) provide early cues to guide the interviewer’s choices of strategies, techniques, and methods from the interview toolkit best suited for that participant.

The game involved the participant and interviewer taking turns to choose from a deck of question cards, and then play the role of interviewer by asking the question printed on the card. Two identical sets of three cards were prepared: one set for the participant and an identical set for the interviewer. The child was given the opportunity to go first by selecting one of her or his cards, and then reading the question to the interviewer, who would answer the question.

Box 2 Interview Card Game**Questions and Example Responses**

Can you tell me a little bit about yourself?

What is your best talent?

If you could have any super power, which super power would you choose?

Sample responses from an interview with a 13-year-old girl

Interviewer (I): If you could have any super power, what would you choose?

Child (C): Make my wheelchair have wings and fly.

I: That sounds like a lot of fun. Where would you go?

C: Around the world.

I: What color would it be?

C: Pink.

The girl who contributed the responses in the above example was sitting in her pink power wheelchair as she made these comments, which provided revealing insight into the ways she had incorporated her wheelchair into her sense of herself, even extending into an imaginary world of possibilities. In another instance, warm-up discussion about imagined super powers opened opportunities for a later discussion about how the participant envisioned “ideal” mobility devices. Thus, while the interview activity card questions did not relate to the research focus (concerning the value of walking and walking therapies), some participants’ responses provided rich insights into disabled children’s identities, and their views about their bodies, mobility options, and assistive devices. One older participant, an 18-year-old youth who had just begun his first year of university, was not engaged by the activity and elected to play the game as follows:

Interviewer (I): You can pick any one of these, and ask me a question first, then, I’ll ask you one.

Youth (Y): I don’t want to ask you anything.

I: Can I ask you one of these?

Y: Sure.

I: I’m going to start with this one: What is your best talent?

Although the youth went along with this one-sided version of the game, his cues were judged to indicate that he was more comfortable participating in ways that he perceived as “adult.” Given these early cues from the participant, the interviewer presented only some of the assembled methods (vignettes and photographs to elicit discussion of preferred mobility choices) and did not present cartoon captioning or role play methods, judging that the youth was likely to view these as childish. This example demonstrates how, in some cases, older teens and young adults who are keen to establish recognition of their advancing maturity might interpret game-like activities as being childish. However, activities such as games, vignettes, and role play might be very engaging for other participants, including adults (Guillemin 2004).

The use of an activity to set the stage for the interview served as a reminder to refrain from making assumptions about participants' developmental skills and abilities based on age or diagnosis. When a 10-year-old participant was unable to read the cards, the researchers reflected on the potential for the activity to contribute to a sense of failure and anxiety for some participants at the very onset of the interview. In all subsequent interviews, participants were offered a choice to read the cards or ask the interviewer to read the cards. In a related example, as the research unfolded, a pattern was noted in instances where the participants tended to repeat the interviewer's responses to the game card questions. This highlighted the possibility that child participants in the study judged the researcher's responses to be appropriate and safe answers. This points to at least some susceptibility for study participants to respond in ways that they perceived to be desirable, or "what researchers want to hear."

3.2 Role Play with Character Dolls or Puppets

Dolls or puppets can be used in qualitative interviews with children to allow them to discuss potentially sensitive issues from the imagined perspective of a doll or puppet through role play (Jager and Ryan 2007; Epstein et al. 2008; Aldiss 2009). Researchers have noted that in studies with disabled children, the doll or puppet's gender, ethnicity, and physical appearance influenced participants' conduct during the interview, suggesting that children might relate more easily to puppets that appeared more "like" them (Epstein et al. 2008). In other research (Teachman 2006), when disabled children were offered a choice of boy or girl puppets, every participant chose his or her same-gender puppet to act out a role play activity. Character dolls were outfitted with splints which the participants appeared to find highly engaging, since many had worn similar splints. In the walk study, participants were offered a choice from among five dolls representative of different genders and ethnicities (different hair and skin color) with arm or leg splints. They could also choose to position the doll with either a doll-sized walker or wheelchair (see Fig. 1).

The following reflective memo describes the participant cues that were used to guide the researchers' decision on whether to include the puppet methods during an interview with a 13-year-old girl:

The girl seemed interested in the puppets as I prepared for the interview. My initial impressions led me to decide to include this role-play activity in the interview, based on my impression of her level of maturity and sense of playfulness. She did quite easily relate to that activity, choosing the blonde, girl doll and placing her in a wheelchair.

Use of the dolls or puppets can be introduced by saying, for example: "We are going to pretend," or "Let's act out a story." Then, a storyline can be set up. In the walk study, this involved explaining that the participant could elect to play the role of a child who had cerebral palsy, while the interviewer would use another doll to play the mother character. One of the dolls was slightly larger than the others and was

Fig. 1 Character dolls/
puppets and mobility aids



dressed to appear more like an adult. The participant was instructed to pretend his or her character was at home watching a favorite television show when their mother interrupts to say that it is time to go to therapy. The interviewer then voiced the role of the mother, animating the doll to emphasize what was being said. Several potential scenarios were prepared with a loosely outlined script that allowed the interviewer to respond with probes during the role play, depending on the emergent dialogue (see Box 3).

Box 3 Sample Role Play Script and Probes

Mother (interviewer): It's time to get ready to go to therapy. I know it's your favorite show, but we need to get going.

Yes, I know you don't want to stop but we'll be late. Don't you want to keep working on your walking?

Let's talk about why you're going to therapy every week.

If you could choose by yourself, whether to go to therapy or not, what would you like to do?

What would happen if you didn't go to therapy?

This scenario was designed to elicit children's views about attending therapy, its role and importance, and the value of walking. Participants' dialogue in the role play

was interpreted as reflective of their understandings of the everyday discourses within their home and school life.

The dolls or puppets were not used with all children in the walk study. The researcher made this decision during the interview depending on the child's cues. A 10-year-old boy in the study showed considerable interest in the puppets, asking about them when he entered the room at the onset of the interview. He engaged immediately with one of the boy-puppets and talked directly to the puppet as well as "through the puppet" within the context of role play. But, the researcher elected not to present this method during the interview with a similarly aged boy of 12. That participant appeared comfortable throughout the interview and engaged with the vignette, photograph, and cartoon methods. But, he repeatedly responded to probes by saying, "I dunno [don't know]" and periodically leaned back in his chair while yawning in an exaggerated way. He denied being tired and appeared more engaged after being given the opportunity to take a break or end the interview (consistent with the researcher's ethical commitment to observe for and address indications of possible fatigue). This participant also frequently ended thoughtful responses by saying, "And blah, blah, blah, blah," as if detached from his own comments. These behaviors can be interpreted as indications that the boy was establishing an identity as a "cool" detached teenager.

Participants and researchers alike can be thought of as performing particular identities during interviews. Fernqvist (2010, p. 1321) similarly described the work of "doing age" where, for example, youth might challenge an interviewer by actively calling on internalized age-related behaviors. This is not to suggest these behaviors are planned, rather they reflect internalized strategies for managing the interview. For example, frequent "I don't know" responses from a young participant who is otherwise sharing rich insightful commentary might be a signal that the topic is uncomfortable. To avoid further discussion, Fernqvist suggests the participant reverts to "doing child"; that is, playing the role of a child who does not have knowledge of importance. In the walk study, the 12-year-old boy's frequent yawning and repetition of the phrase "blah, blah, blah" were interpreted as indications that he was asserting himself by "doing teen," and strategies to deflect dialogue about feelings and topics that were less comfortable. The young participant shared rich, detailed descriptions about walking, mobility devices, and therapies despite his frequent "doing teen" responses and behavior.

3.3 Cartoon Captioning

Cartoon captioning is a projective technique developed with adult participants in market research (Broeckelmann 2010; Doherty and Nelson 2010) and in educational research with children and adults (Warburton 1998; Catterall and Ibbotson 2000). In this method, participants are presented with a cartoon drawing and asked to fill in

empty “speech bubbles.” This method is especially engaging because of its novelty because it generates curiosity, while being conducive to interaction (Catterall and Ibbotson 2000). Participants must imagine how others might respond to the situation portrayed in the cartoon, in much the same way as vignette methods which are described later in this chapter.

In the walk study, the cartoon captioning method was engaging and elicited perspectives that might otherwise have been missed. However, some children in the study struggled to compose captions. They responded with one or two words, and were unable to say more when probed. It could be that some participants thought their responses needed to be humorous and found this intimidating. As well, the cartoon images were not amenable to adaption so, for some participants, the cartoon scenarios might have been unfamiliar experiences, making it more difficult for them to respond meaningfully. An example cartoon-completion activity from the walk study is shown in Box 4.

Box 4 Example Cartoon Completion



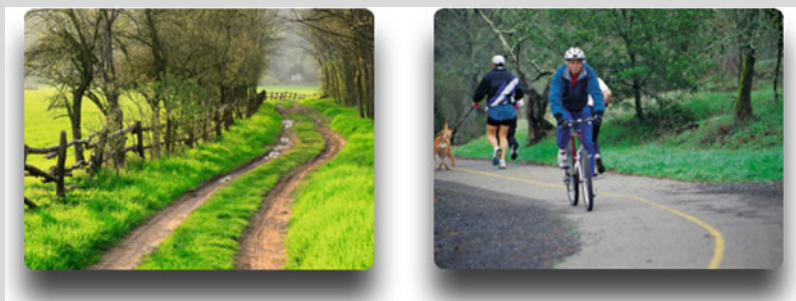
In the example in Box 4, two youths of indeterminate age are illustrated on a sidewalk. One, a girl, is seated on a power scooter; the other is a boy holding a skateboard. The speech bubbles above their heads were either partially completed or left blank. The activity was included toward the end of the interview, and modified depending on the sophistication of language and other cues from the participant. Participants were to comment on how they might complete the cartoon. A 9-year-old boy in the study responded this way:

- Scooter girl (G): Let's have a race.
 Skateboard boy (B): No, I don't want to race.
 G: Why not?
 B: Because I hate racing you because you go faster than me.

3.4 Photo-Elicitation

Photographs brought into an interview by a researcher can help scaffold and elicit dialogue with children (Morrow 2001; Kirk 2007). In the walk study, a series of photographs of everyday environments were selected to represent spaces that children and youth might navigate (See Box 5). The series included several variations of school classrooms, a school gymnasium, an outdoor playground, a home kitchen, a sidewalk, and various park or natural environments. These were presented in sequence as a slide show presentation on a laptop computer to elicit discussions about participants' mobility challenges and preferences. Youth were asked a series of questions related to ways they would choose to mobilize in each environment. The photographs proved to be effective in prompting rich discussions with all participants, and further, the concrete nature of the activity seemed to provide a break for some participants from more challenging discussion of abstract feelings. For example, the photo-elicitation method seemed to reduce anxieties evidenced by a 10-year-old boy who appeared to struggle with some of the concepts discussed in the interview. He was quick to say, "I don't know." However, he relaxed and appeared very engaged when using the laptop computer to scroll through and comment on the photographs. The images contextualized the discussion in a very concrete way that helped him to feel more confident in responding.

Box 5 Photo-Elicitation Examples



In another instance, a 12-year-old boy immediately appeared more engaged when presented with the photographs, as described in an extract from the researcher's interview notes:

The boy, who had been acting bored and frequently yawning, became very engaged by the photographs. I used language like: "If you were right inside this picture, how you want to move about?" or "How would you like to get around if you were right here?", because he was actually touching the screen, asking, "Where am I in the picture?" He seemed to be imagining himself in the picture so I tried to match my prompts to his cues.

3.5 Vignettes

Vignettes are short scenarios that set up a specific context and situation that requires some type of response or resolution by imagined characters. They help elicit participants' values, meanings, and beliefs (Finch 1987) about the topic of inquiry. Vignettes have been described as a method that allows interviewers to combine a "systematic structured approach with the expression of 'emic' or personal meanings" (Miles 1990, p. 38). The method was developed for use with adult research participants who were asked to write a series of vignettes based on their own experiences to record and reflect on specific situations and experiences. Researchers noted that an advantage of the methods was that participants' vignettes reflected common experiences which when shared, conveyed to the reader a sense that "I am not alone" (Miles, p. 41). The method has since been modified so that researchers provide prewritten vignettes during an interview and ask participants how they might resolve the described situation (Barter and Renold 1999, 2000; Wilks 2004). Vignettes should be constructed to resonate with participants' experiences but remain ambiguous enough to prompt judgments, decision making, and descriptions of the views or experiences that influence participants (Barter and Renold 2000).

In the walk study, vignettes were paired with an image of a child who resembled the participant (in relation to gender, age, and mobility device used). The purpose of this pairing was to provide a visual representation that could contextualize the vignette and help engage the child participant. Vignette details were modified to reflect each participant's situation and experiences, based on prior discussion with a parent. A sample vignette appears in Box 6.

Box 6 Sample Vignette

I want to tell you a story about Andrew. This is Andrew in the picture. (Show generic photo of boy using wheelchair.) He is in Grade 3 and he has CP [cerebral palsy] – like you do. He does some things at school differently than the other kids in his class but mostly he tries to be the same as the other kids. One thing that is different for Andrew is his walking – he uses a walker and he needs extra time to get around his school. Sometimes, he has a hard time keeping up with the other kids. Lots of times, he gets tired and must take a rest. He gets upset about that. One day last week, his teacher said, "I think that you should use your wheelchair when we go out for recess."

Probes included:

What do you think Andrew will say?
 How do you think he will feel about it?
 What does he decide to do?
 Do you have a story like that?

In the walk study, participants all acted engaged and responded easily to the vignettes. The method evoked descriptions of children's similar personal experiences along their views and feelings about those experiences, shifting with ease between sharing their views about the vignette and their views of their own experiences. The method was especially effective in eliciting discussion about ways that children in the study viewed themselves and wished for others to view them, as illustrated by an example in Box 7.

Box 7 Sample Vignette Response

A 12-year-old girl commented on the importance of using her walker and standing tall, which she identified as a highly valued aspect of being "like everyone else." She shared that when using a walker, she felt people saw her as being the same as everybody else who walks. She contrasted this with concerns regarding how others view her when she is using her wheelchair:

Child (C): I like that I get exercise, 'cause everybody else walks. I don't want to be like a person that doesn't walk at all.

Interviewer (I): Is it important to try to be like everybody else when you can?

C: Yeah, yeah, it's pretty important to me.

I: What do you think it would be like for somebody like the girl in the story if she used the wheelchair?

C: Well, she knows that she can walk; it's just that people see that she maybe can't walk. She keeps having to tell people that, like, she can walk. It's just that she doesn't.

GT: What about the walker – do you think that about the walker?

C: No, because they see that I just use it for, like support, and not for, just using it. Do you have a story like that?

3.6 Sentence Starters

Sentence starters are used as an interview method when a participant is having difficulty initiating responses. Using this technique, researchers can give children permission to talk about sensitive topics or to express views that they might otherwise deem "inappropriate" to express to an adult. The method also tends to decrease the sense that the participant is under pressure to identify and share his or her own views, because the interviewer is responsible for beginning the sentence and the sentence can be framed as a general rather than personal statement.

Box 8 Example Sentence Starters

In the walk study, instead of asking participants to specify whether they liked or disliked elements of their own therapy, participants were asked to complete sentences such as:

"The best thing about therapy is. . ."

"The worst thing about therapy is. . ."

The method might prompt concerns that research participants will be led toward specific responses. However, in the walk study, children and youth responded to the sentence starters in a variety of ways, including deflection of the topic area. The following excerpt from an interview with a 12-year-old girl demonstrates that the technique does not necessarily lead participants toward a predictable response:

- Interviewer (I): I think you've also tried some Botox? [a drug injected to treat muscle spasticity]
- Child (C): Yeah.
- I: Okay. So, if I said, "I like Botox because. . .," Can you fill in that blank? "I like Botox because. . .".
- C: Ah, no, I can't say anything.
- I: Okay, that's fine. How about this one: "I didn't like Botox because. . ."
- C: Because it's, um, painful, and it's like, for me it doesn't really help anyways . . . I just have them because sometimes it helps, but sometimes it doesn't.

This sequence of responses, generated using sentence starters, helped elicit more in-depth discussion where the girl explained her feeling about this treatment and her motivation for complying, even though she was uncertain of its effectiveness. Her responses provided insights into her perspective about the relative merits of the treatment that might not have otherwise been discussed in the interview.

The methods set out here could be thought of as a toolkit that, once assembled, can be used to optimize data generation with disabled children through individualized, flexible interviews, dynamic interactions, and rich information exchanges. When combined, the methods provide opportunities to shifting the focus of an interview from the participant's experiences and beliefs to a projected "other" whose imagined views and actions are informed by the participant's own experiences, beliefs, and understandings. In doing so, the methods collectively function to add aspects of fun, and help create a comfortable space for children to share their views.

4 Partnering with Parents

Prior to involving children in an interview, it is helpful to have some contextual knowledge of the participant's life and circumstances. This can help the researcher identify specific areas that might have resonance for that individual child. Working with parents prior to an interview to learn about the preferences of the child can also be important to identify strategies that might contribute to the child's comfort in the interview and therefore, optimize the data generated (Irwin and Johnson 2005). The importance of partnering with parents in research with children has also been noted by Barter and Renold (2000) who, in a study of peer violence among in residential

children's homes, reported that study participants were better able to engage in discussion when they had experience with the situations depicted in the vignettes.

Initially, in the walk study, limited demographic information about study participants was elicited through a phone conversation with parents prior to the interviews (age, diagnosis, and walking ability). Reflecting on the interview process, it became apparent that to increase the depth and quality of the data being generated, the interviewer needed more contextual information about the child's current and recent therapies, their school placement, their typical modes of mobility, and the assistive devices they used. In subsequent interviews, this information was elicited in conversation with a parent prior to conducting the child interview. The background information helped the interviewer more readily adapt elements of the methods described earlier in this chapter. For example, role-play and vignette activities were individualized to include familiar types of therapy, similar school settings, and narratives that were likely to resonate for the child or youth participant. The following extract from the interviewer's notes describes an example from the study:

I had followed through on the idea of getting a little more information ahead of time from the parent to allow me to customize the role-play and other vignette activities, to assist the child to draw from their own experiences and project these onto the characters. This appeared to be very helpful today, as the young girl commented: "Just like me!" on hearing the vignette and when asked, "Do you have any stories like that?" she readily described similar situations that she had experienced.

Parents can be a valuable resource and contribute toward establishing a supportive and comfortable interview frame that acknowledges the interdependence of family members. It is important to differentiate this strategy from one where a parent's comments are interpreted as representations or proxies of the child's viewpoints. Rather, information shared by parents serves as a point of departure for later engagement with the child participant and helped optimize conditions where they were supported represent their own views about the topic of inquiry.

5 Child-Researcher Power Relations

Conducting interviews in a child's home is desirable as it can aid in addressing power differentials and creating rapport. It also has the advantage of maximizing opportunities to observe participants in their preferred personal space. These advantages come with some degree of unpredictability (MacDonald and Greggans 2008). For example, a child who might struggle to sit in one place throughout an interview will be more likely and able to move about in the familiar home environment than would be possible in a stark, institutional space. This can lead to what Irwin and Johnson termed "kinetic conversations" (2005, p. 826).

In the walk study, whenever feasible, interviews were conducted in the child's home and participants were invited to select a location within their home for the interview. One 10-year-old boy chose his hockey-themed bedroom; the location

helped establish a sense of intimacy, comfort, and privacy, where he readily took charge of aspects of the interaction. During the interview, he frequently pointed to furnishings, photographs, and other favorite possessions to illustrate a point he was making. The setting and the artifacts it contained elicited novel dialogues, and contributed rich descriptive data through interviewer observations. Effectively, the setting allowed the participant to host the interviewer, sharing power, at least to some extent, within the interaction. In another situation, an interview was conducted with a 13-year-old girl while the family home was being renovated and in conditions that involved significant noise and interruptions. Still, the home setting provided contextual grounding and opportunities for discussion that another location would not have elicited. The participant's excitement about the renovations led to discussion about an elevator that was being installed to make her home more accessible. This opened further dialog about walking and mobility issues, which was the focus of the research.

Research with disabled children necessitates ongoing reflexivity on the part of the interviewer in relation to the power differential between researcher and child participant. Many novice interviewers wonder how they should present themselves and their research aims. Christensen suggested that child interviewers "take on and perform themselves as an unusual type of adult, one who is seriously interested in understanding how the social world looks from children's perspectives but without making a dubious attempt to be a child" (2004, p. 174). It is also helpful to aim for rapport that connotes a working relationship between the child and the interviewer, as opposed to a friendship with the child (Irwin and Johnson 2005). Being mindful that children are actively encouraged not to talk to strangers, interviewers might expect to encounter some difficulty in building rapport with young children, especially during a first or single interview. However, disabled children and youth, being accustomed to the attentions and interventions of numerable adult professionals, might be more inclined to go along with professionals even – perhaps especially – when it is uncomfortable, because they have internalized understandings that it is "for their own good." Boundaries around privacy and trust might be blurred. Therefore, researchers should reflect on whether this group of young people might be more trusting of interviewers and less guarded about sharing intimate, personal insights into their worldviews than other groups of youth. Interviewers should take extra steps to explain and model ways that children can assert their rights as research participants.

By providing a range of methods within a single interview, researchers can be better prepared with options to reduce a child's anxiety about providing "right" answers and facilitate opportunities for comfortable dialogue – sometimes with the interviewer and sometimes with imagined characters or peers. Researchers typically review parameters for participating or withdrawing from research with participants. But, interviewers can go further by explicitly rehearsing with participants options for signaling that they want to stop, take a break, or refrain from answering a question. Children who have learned to defer to adults might not easily act on their option to withdraw. In the walk study, this was addressed through detailed scripted examples (see also Kirk 2007), such as, "If you don't want to talk about something, you can

just say, ‘I don’t want to talk about that,’ and it will be okay.” The interviewer explained that she would interrupt and ask specific questions if the youth showed signs of fatigue or seemed anxious. These reminders served to demonstrate that the participant and interviewer would share responsibility within the interview.

6 Conclusion and Future Directions

This chapter has introduced a methodological approach for combining and adapting interview methods to optimize the quality of data generated during single interviews with disabled children and youth. The importance of partnering with parents early in the process has been highlighted. Parents can provide important contextual information that will aid researchers in building rapport and providing a supportive, safe interview frame wherein children and youth can tell their own stories and share their views. Just as Kortessluoma et al. (2003, p. 440) emphasized, “children certainly know more about what they know than interviewers do”, researchers will do well to acknowledge that parents know far more about their child than interviewers do. Multiple sources of information, when used reflexively, can enhance data collection and interpretation. Partnering with parents prior to an interview can get the interviewer “into the same ballpark,” so that they are introducing topics and asking questions that likely resonate with individual children’s experiences. This approach might be equally helpful in some research with adults, for example, when adult participants have difficulties with communication.

The methodological approaches reported in this chapter reflect learning from a small pilot study with children with disabilities across a relatively wide age range. Even though individual children and youth of a certain age might tend to be more comfortable with certain methods, it was optimal to be prepared to select and combine methods within an interview based more on the participant as an individual than on his or her age or diagnosis. The assembling of multiple interview methods allows the interviewer to take on an improvisational approach during interviews that is responsive to participants’ unique experiences, contexts, abilities, and ways of communicating, as well as the evolving interactions within each interview.

It is important to conclude the chapter by noting that the quality of data generated through interviews with children (and adults), regardless of method, is always reliant on the skills of the interviewer; the methods are an adjunct to those skills. The approach to interviews outlined in this chapter could be used in interviews with participants of varying ages and abilities. These methods and approaches have since been used, and continue to be refined, in several subsequent studies involving disabled children in interviews about various aspects of children’s rehabilitation.

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Participant-Generated Visual Timelines and Street-Involved Youth Who Have Experienced Violent Victimization

117

Kat Kolar and Farah Ahmad

Contents

1	Introduction	2042
2	The Study: Methodological Considerations	2044
2.1	Study Setting and Design	2044
2.2	Data Collection	2045
2.3	Data Analysis	2046
2.4	Participant Demographics	2047
3	Timeline Implementation: Introducing Timeline Mapping to Participants	2047
4	Timeline Styles	2048
5	Thematic Findings	2049
5.1	Theme 1: Rapport Building	2050
5.2	Theme 2: Participant as Navigators	2052
5.3	Theme 3: Therapeutic Moments and Positive Closure	2053
6	What We Have Learnt	2054
7	Conclusion and Future Directions	2057
	References	2058

Abstract

Despite growing interest in the use of visual methods as a way to engage with issues of representation, meaning, and power relations in qualitative research, only limited literature is available on the use of participant-generated imagery in guiding or supplementing semi-structured or open-ended interviewing methods in the health and social science disciplines, or in navigating issues of interviewing vulnerable persons who have experienced trauma. We draw from a study

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exploring resilience among street-involved youth to investigate how participant-created visual timelines inform verbal semi-structured interviewing with persons who have experienced personal victimization in the form of violence, as well as structural marginalization. To guide future research efforts, the process of timeline implementation is discussed in depth. Analysis of timelines was conducted through a critical emancipatory research lens. Three overarching themes developed through analysis of timelines are explored here: (a) rapport building, (b) participants as navigators, and (c) therapeutic moments and positive closure. In the discussion, we engage with the potential of visual timelines to supplement and situate semi-structured interviewing and illustrate how the framing of research is central to whether that research facilitates increased participant authority in the research process, enhances trust, and ensures meaningful, accountable engagement.

Keywords

Resilience · Timeline · Visual methods · Street-involved youth · Qualitative interviews

1 Introduction

In qualitative research, visual methods encompass analysis of a wide variety of mediums, from found images and visual objects to the use of participant-generated imagery (i.e., imagery that was produced by participants specifically within the context of a research study) (Rose 2001; Guillemin and Drew 2010; Pauwels 2010; Jackson 2012). Despite growing interest in the use of visual methods as a way to engage with issues of representation, meaning, and power relations in qualitative research, only limited literature is available on the use of participant-generated imagery in guiding or supplementing semi-structured or open-ended interviewing methods in the health and social science disciplines, or in navigating issues of interviewing vulnerable persons who have experienced trauma (e.g., Guillemin 2004; Goodrum and Keys 2007; Umoquit et al. 2008; Bagnoli 2009; Horsfall and Titchen 2009; Berends 2011; Patterson et al. 2012). This research has contributed to the understanding of potential uses and strengths of visual methods, including the building of rapport, enhanced contextualization of narratives, and nonverbal communication as a way to access “othered” ways of knowing. However, detailed exploration of the implementation and use of visual methods with marginalized groups is still required. Also essential is critical engagement with the ways in which visual methods may inform or pose new concerns for the researcher-participant relationship.

This chapter contributes to the growing literature on visual methods and participant-generated imagery by providing an analysis of the implementation and findings of a study using participant-created visual timelines and semi-structured interviewing to explore resilience among street-involved youth in Canada’s Greater Toronto Area [GTA]. Timelines are a visual, arts-based data collection method, derived from a broader framework of graphic elicitation designs (Umoquit et al.

2008; Bagnoli 2009; Sheridan et al. 2011). Timelines are created from a participant's life events, placed in some sort of chronological arrangement, with visual indication of the significance or meaning attached to highlighted events (Berends 2011; Patterson et al. 2012). The aims of this chapter are to examine the potential of participant-generated visual timelines to supplement and situate semi-structured interviewing with marginalized groups, as well as to provide guidance for health and social science researchers regarding implementation of timeline mapping (see also ► Chaps. 67, "Timeline Drawing Methods," ► 70, "Body Mapping in Research," and ► 71, "Self-portraits and Maps as a Window on Participants' Worlds").

The use of in-depth narrative interviews on sensitive topics or with marginalized groups not only rouses concerns regarding potentially exploitative research relationships, but also involves issues regarding development of rapport (here understood as accountable, meaningful engagement with participants (see Holland 2007; Liamputtong 2007; Nicholls 2009). We recognize that interviews may elicit anxiety as participants reflect on and share potentially traumatic or difficult experiences (Hollway and Jefferson 1997). Researchers must work to ensure that any potential distress which may be caused by study involvement be minimized for participants. To address these concerns, selection of research methods must involve critical consideration of how these methods structure power dynamics between the researcher and participant. In addition, by prioritizing reciprocal engagement of participants such that they have say in how the research proceeds, researchers can facilitate increased participant authority in the research process and enhance trust and meaningful, accountable engagement (Holland 2007; Karnieli-Miller et al. 2009; Nicholls 2009).

Qualitative methods can be integrated to make data collection situations more amenable to participants who have experienced marginalization, as well as to allow diversified exploration and representation of participant life experiences (Kesby 2000; Umoquit et al. 2008; Patterson et al. 2012; Liamputtong 2013). The combination of graphic elicitation methods such as visual timelines with verbal interviewing provides one such possibility to address these issues. Timelines have been used to explore a wide variety of issues, including the trajectory of substance abuse and treatment (Berends 2011), the impact of financial incentives on clinical behaviors (Umoquit et al. 2008), and barriers to health of people experiencing homelessness (Patterson et al. 2012). The available visual methods literature suggests that use of timelines in tandem with in-depth narrative interviews may enhance the data collection experience and data quality, particularly when researching sensitive topics or marginalized groups (Harper 2003; Berends 2011; Sheridan et al. 2011).

Although this literature has begun to assess some of the strengths and limitations of visual timeline implementation, much remains to be elaborated on how sources of data, topics of investigation, and epistemological approaches all inform timeline interview processes and outcomes. Academic articles on timelines focus largely on the content of timelines at the expense of what their form contributes to an understanding of various social phenomena (exceptions include Bagnoli 2009). Some researchers note that they could not include individual timelines due to ethical issues (e.g., Berends 2011), could only provide researcher-created timelines after interviews had been completed (e.g., Patterson et al. 2012), or were limited to the use of

prestructured diagrams in the interview (e.g., Umoquit et al. 2008). Berends (2011) suggests that the increased availability of research utilizing visual methods is necessary because analyses of individual timelines in combination with supporting interview text will facilitate more holistic understandings of data by readers. Further, considering the overall lack of participant-generated timeline implementations with groups who experience social structural marginalization, it is clear that research on use of timelines across more varied populations is still required to understand differences in uptake and response to this method. To speak to these gaps in the timeline literature, here we provide an in-depth critical discussion of our implementation of timeline mapping with street-involved youth. We also conducted a parallel study using timeline mapping with South Asian immigrant women who were survivors of partner violence; the details are presented elsewhere given the focus on street-involved youth for this chapter (see Ahmad et al. 2013; Kolar et al. 2015).

2 The Study: Methodological Considerations

2.1 Study Setting and Design

This study was conducted in the city of Toronto, in collaboration with a community agency serving street-involved youth in 2010. Dr. Patricia Erickson, a researcher on the study team, had done considerable prior research on street youth issues with this community agency. She met with agency staff at an early stage of study planning in order to explain the project and gain their participation, and also committed to returning and presenting the findings when data collection was complete (Kolar et al. 2012).

A critical emancipatory and feminist lens guided the implementation and analysis of this research project (Kolar et al. 2012; Ahmad et al. 2013). Such a lens values power-conscious epistemology where the interview is approached as an active, co-constructive process between the participant and researcher. This perspective moves a researcher away from conventional approaches that treat interviews as pipelines between the research “subject,” positioned as the passive conveyor or object of knowledge, and the researcher who is the source of objective authority eliciting information (Smith 1990; Kesby 2000; Nicholls 2009; Gringeri et al. 2010; see also ► Chaps. 118, “Capturing the Research Journey: A Feminist Application of Bakhtin to Examine Eating Disorders and Child Sexual Abuse,” and ► 119, “Feminist Dilemmas in Researching Women’s Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise”). Emphasis is placed on participant narratives by asking simple, open-ended questions and active listening by the interviewer. This lens requires that reflexivity be a central practice, whereby researchers critically engage with how the very production of knowledge and interaction with participants is situated in social relations and power inequalities. For our analysis, this involved looking to how the experiences of street-involved youth – experiences and social locations which are conventionally marginalized – could be given voice in ways that addressed the concerns and interests of participants. Our study sought to understand how timelines in in-depth interviews could provide a venue for participants to tell their

stories and how timelines could be used to recognize and legitimize participants' understandings of resiliency (Maxwell 1992; White and Klein 2008).

For this study, a qualitative design of face-to-face, in-depth interviews was employed. The interview guide was developed through review of literature addressing resilience and concerns specific to street-involved youth, from available literature on timeline implementation (particularly Bagnoli 2009), and through consultation with the collaborating agency serving street-involved youth in Toronto. The interviews were shaped around a semi-structured interview guide with open-ended questions on resilience, defined as resources (internal or external) that may assist individuals in their engagement with and navigation of adversity (PreVAiL 2010; Kolar 2011). Farah Ahmad, as a research team member, conceptualized the inclusion of timeline mapping as meeting the critical emancipatory and feminist perspectives of the research. This investigation of resilience was intended to disrupt benchmarks of positive adaptation that frequently reflect values of White, middle-class families (Ungar 2004). Such benchmarks are particularly problematic for those who have lived in resource-limited and volatile contexts, such as street-involved youth (Ungar 2004; Kolar et al. 2012). Interview questions were accordingly intended to encourage participants to identify what constituted a "resilience resource." For example, interview questions included: "Can you draw a timeline depicting events that were important in your life?" and "Can you tell me if there were other supports that you wish you had when you were going through this difficult time?" A short sociodemographic survey was conducted with participants prior to commencing the in-depth interviews. The collaborating agency reviewed the study protocol and provided feedback. Research ethics approval was obtained from the University of Toronto.

2.2 Data Collection

This study was designed to be exploratory, aiming to develop a contextually appropriate understanding of resilience in relation to the specific challenges faced by street-involved youth. Thus, sampling was not aimed at identifying a "representative sample" of street-involved youth in Toronto, but rather at inductively exploring variation in experiences of resilience and generating new insights through in-depth investigation. For exploratory studies, a small number of cases are recommended (i.e., fewer than 20) (Kuzel 1999; Crouch and McKenzie 2006). Youth between 18 and 26 years of age were eligible to participate if they had experienced street-involvement, had experienced violence since becoming street-involved and/or had experienced childhood maltreatment, and viewed themselves as having made "positive changes" in their lives. It is recognized here that what constitutes contextually appropriate indications of positive development will be different for street-involved youth in comparison to the general population due to the volatile and often dangerous social environments street-involved youth occupy, and structural barriers that they face. Through collaborating discussions between researchers and agency counselors on identifying contextually appropriate understanding of resilience for street-involved youth, "positive changes" were determined

to mean that participants have been engaging in activities that promote their mental health, well-being, and coping, including: (a) addressing addictions and past trauma, (b) establishing more supportive relationships, and (c) pursuing goals such as education, stable housing, or employment. Counselors at the collaborating agency identified participants meeting these criteria and provided potential participants with preliminary information about the study in the form of flyers. Interested participants contacted the study coordinators for further details (for more information on sampling, see Kolar et al. 2012).

Interviews with street-involved youth were held in a private space provided by the collaborating agency and were conducted by one team member (Kat Kolar). Prior to proceeding with interviews, the interviewer discussed the in-depth interview process with each participant, provided them with a copy of the consent information sheet, and then gave a verbal overview of the consent sheet. The interviewer addressed any questions or concerns of participants before obtaining verbal consent to proceed. The verbal consent process was used in order to reinforce the anonymity of participants, as no record of participant names was kept post interview in any file. Participants also received an honorarium of 30 dollars. One interview was conducted with each participant, with interviews lasting 90 min on average. Interviews were tape recorded and transcribed, and visual timelines were kept by the interviewer.

Upon completion of each interview, the interviewer was asked to write a research memo wherein they reflected on her experience of the interview. This involved thinking about the tone or mood of interaction between the interviewer and participant, the impact of the study focus of resiliency on the interview process, the impact of the use of timeline mapping on the interview process, and consideration of how participants engaged in the timeline mapping activity, as well as of interviewer thoughts or feelings on timeline mapping. These reflection notes were instrumental to the reflexive engagement of researchers with the process of knowledge production in this study.

2.3 Data Analysis

The study data included transcribed narratives of the participants, the timeline maps, and interviewer reflection notes. These were thematically coded (King and Horrocks 2010). The thematic open coding framework was developed to investigate how timelines could assist researchers in better understanding the experiences discussed by participants and how timelines shaped the data collection process. Coding involved analysis of both *content* and *form* of data using a two-stage team-based approach and was conducted by hand. Primary open coding was conducted by one team member (Linda Chan) who was not involved in data collection. This initial set of codes was then reviewed and refined by all team members over the course of several group meetings before consensus on codes was reached. All participant names provided in this manuscript are pseudonyms.

In the following sections, several salient issues that emerged from our study will be discussed. These include: a description of timeline implementation, an overview

of timeline styles, and the themes identified in exploring the impact of timeline mapping on interview dynamics.

2.4 Participant Demographics

It is essential to briefly describe the demographic characteristics of the participants in our study. All participants described themselves as survivors of violence who had experienced homelessness. Participants were 19–26 years old and reported diverse ethnic origins (self-identifying as White, Black, Aboriginal, East Indian, or Latino), with half of them being born outside of Canada. Most had high school education and an annual income of less than 10 thousand dollars. Eight of the ten participants reported having access to housing at the time of the interviews. Detailed descriptions of participant demographics and experiences of resilience have been reported elsewhere (Kolar et al. 2012).

3 Timeline Implementation: Introducing Timeline Mapping to Participants

To introduce the timeline method to participants, the interviewer began by providing a brief description of the timeline as a tool that is intended to assist researchers in better understanding the important life experiences of participants, particularly by showing a more holistic picture of life events than can often be captured in one-time verbal interviews. The research team anticipated that some participants may be confused by verbal instructions to draw a timeline or may be uncomfortable with this request due to feeling that they have poor drawing or writing skills. In order to make participants more comfortable with the potentially unfamiliar task of drawing a timeline, participants were then shown sample timelines created by the interviewer. These sample timelines were intended to help stimulate creative engagement by participants and to provide them with a sense of flexibility for creating their own timelines, while simultaneously reassuring them that there was no “wrong way” to create a timeline and that spelling was not a concern. The interviewer emphasized that timelines did not have to be done in any specific way and so were not prestructured. Sample timelines took a variety of forms, including simple straight lines, text-heavy lists, and nonlinear representations such as swirls and undulating lines. These instructions were intentionally broad because of the exploratory nature of this study, aiming to identify resilience processes and resources among street-involved youth that cannot be captured by prestructured resilience scales, as these scales fail to account for the context-specific struggles and successes of marginalized groups (Kolar et al. 2012).

Upon explaining the timeline method and answering any preliminary questions on how to proceed, the interviewer gave the participant a pen and large sheet of paper and asked the participant to begin the timeline when they felt ready to do so. Participants created their own timelines. Direct involvement of the interviewer in timeline creation was minimal. The interviewer sometimes contributed to timeline creation when

requests were made for direct assistance (e.g., spelling) and also provided reassurance when participants expressed confusion about how to create or organize their timelines.

In this study, timelines were created in two stages. In the first stage, the interviewer introduced the interview format by asking participants to draw the timeline while thinking about indicating the:

...important events that stick out in your mind when you reflect on your life. It can be the first time you slept on the street, it can be a time that you were really hopeful or satisfied. . .

Once participants indicated that they had completed their timeline, the interviewer then probed about several life events that participants had identified in their timeline map in order to build contextual detail during the remainder of the interview. The timelines thus continued to play a central role throughout the interviewing process, with participants often adding contextual details to their timelines as the interview proceeded.

Towards the end of the interview, participants were asked to add another section to their existing timelines which indicated their goals and expectations for the future and then were asked to discuss these with the interviewer. This “future timeline” was the second stage of the timeline mapping process implemented in this study.

4 Timeline Styles

Two distinct timeline mapping styles were prominent from the variety of timelines created by the participants: the list-like timeline (Fig. 1) and the continuous-line timeline (Figs. 2 and 3). Square brackets in the timeline figures indicate information that has been anonymized in order to preserve participant confidentiality.

List-like timelines were text-heavy and tended to describe life events chronologically (see Fig. 1). These timelines consisted of columns with brief notes (e.g., short phrases and keywords) with or without dates (e.g., according to participant ages, the year an event occurred, or time periods as indicated by holidays or seasons). Some participants separated positive and negative life events into different columns or used signs and symbols (such as positive (+) or negative (−) signs or emoticons (such as “smiley faces”)) to indicate how they felt about these events or how they perceived these events to have impacted them. Some participants also used dots or Xs to mark important events on the timeline. Some of the timelines provided below have been previously published (see Kolar et al. 2015).

Several participants created continuous-line timelines: they drew a line and used spikes, dips, angles, waves, and curves to represent positive or negative dimensions of their experiences (see Fig. 2). Most of these continuous timelines were constructed horizontally. Similar to the list-like timelines, some participants used dashes, dots, or Xs to indicate events significant to them. Often, this timeline was complemented with varying types of notes and dates, either below, above, or beside the continuous line.

Other timeline styles included a unique hybrid of the continuous-line and list-like timeline styles (see Fig. 3). For instance, one timeline (not shown in this chapter)

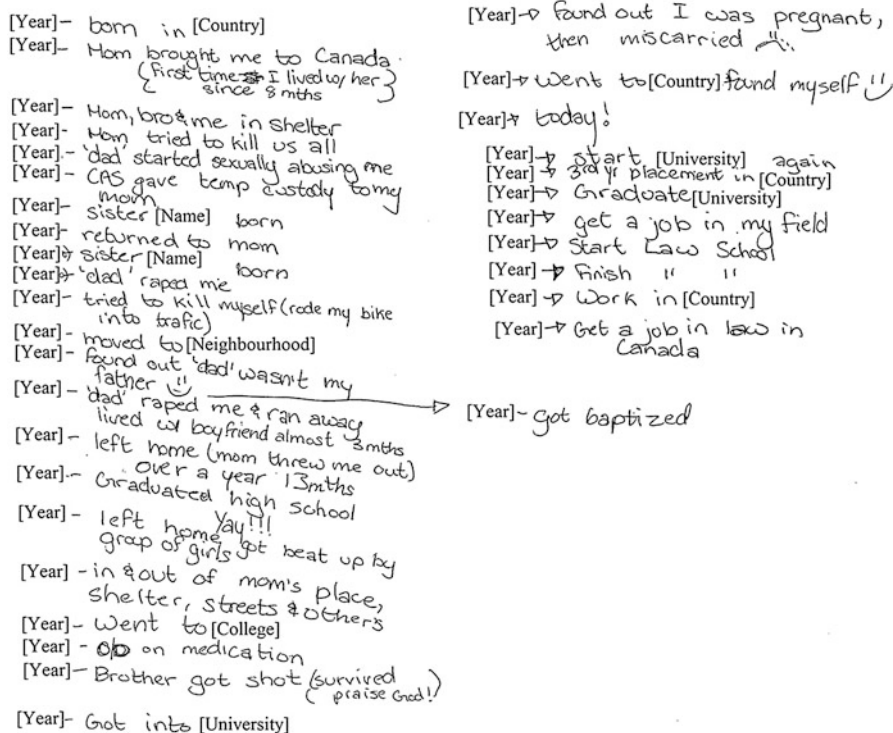


Fig. 1 List-like Timeline

entailed a continuous line with a list of years from the participant's birth to the present. In this timeline, the participant expanded upon the difficult or tumultuous years he experienced by adding a list of significant events underneath the year these events corresponded with. This participant also drew several pictures underneath these tumultuous years. The participant described his timeline as "messy" and explained that this messiness depicted the complexity of many of his life experiences.

5 Thematic Findings

Here, we discuss three themes that were identified in our coding of timelines, interviews, and interviewer reflection memos. First, the use of timelines encouraged *rapport building* by reducing traditional hierarchies of a research interview. Second, timeline mapping allowed the *participant to navigate* the interview space through reflection and boundary setting around their experiences. Finally, the use of timelines facilitated *positive closure* to many of the interviews by providing participants with an opportunity to envision future timelines in light of their survivorship and resiliency.

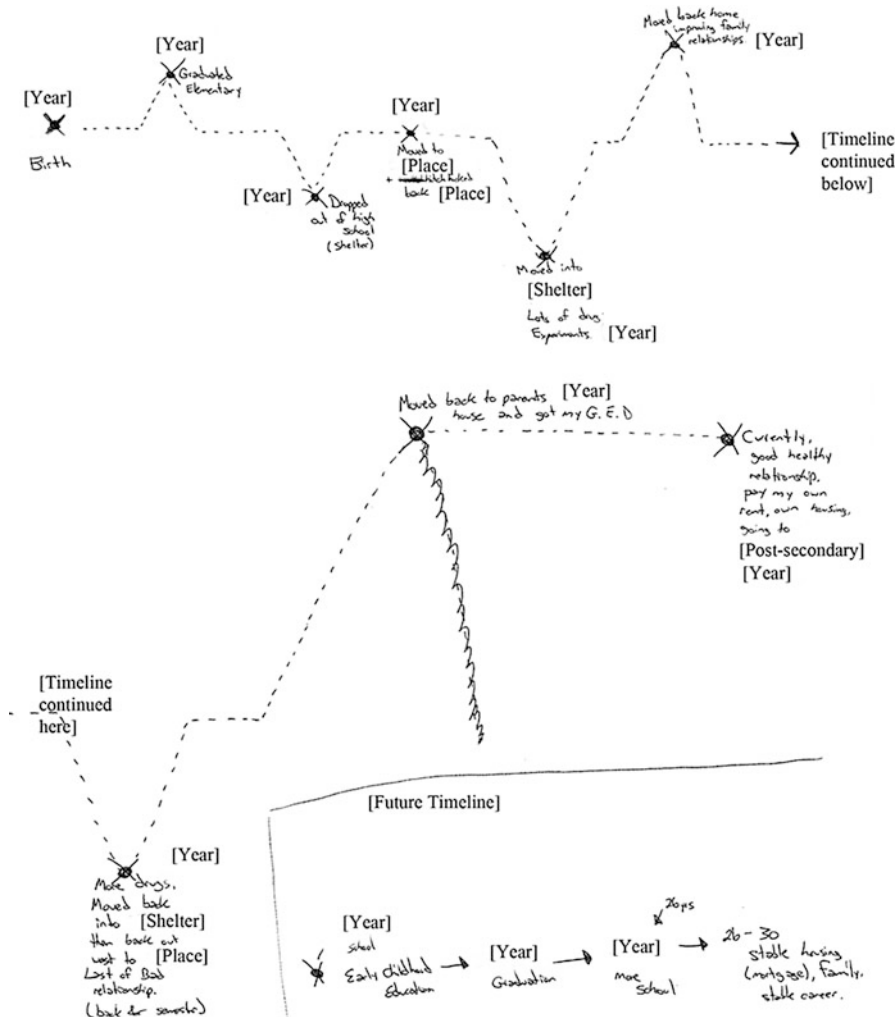


Fig. 2 Continuous-line timeline (Previously published in Kolar et al. 2015)

5.1 Theme 1: Rapport Building

Analysis of timeline narratives reveals that rapport building between the interviewer and participants was mediated by a *life-story* approach taken by participants, purposeful use of *topic-shift* and *self-disclosure* by the interviewers, and the *interactive* nature of the timeline. The rapport-building theme was supported by interviewer reflections as well.

Participants took a life-story approach when mapping their timelines. This open-ended approach allowed them to share significant life events unobtrusively while the interviewer became an involved listener. This style of conversation

As noted above, the introduction of the timeline by the interviewer included several examples of how one may draw a timeline. The interviewer also briefly shared her personal timeline with participants and used humor to describe the appearance of her own timeline in order to convey a relaxed attitude towards what a timeline could look like. Interviewer self-disclosure and use of humor led to a more comfortable start to the interviews and so enhanced rapport.

The *interactivity* of the timelines facilitated a sense of participant comfort and momentum in the interviews. The interviewer encouraged participants to reflect on major life events in creating the timeline. For example, the interviewer assured participants that “you don’t have to worry about missing anything, because you can always add stuff in [to the timeline] while we’re talking” (to Jordan). Likewise, the interviewer supported participants in generating timelines by giving suggestions during descriptions of their life stories. For instance, Jade iteratively constructed her timeline, filling in details on the timeline regarding how her experience of homelessness changed over the course of several years while she verbally described these experiences to the interviewer who probed for contextual details:

Jade: [After being in the hospital] I went to [a shelter] and it was an interesting place. It was just for women . . . I was the only person who wasn’t like, smoking crack in the building.

Interviewer: When was that? Was that in [year], then?

Jade: Yeah, Christmas would have been [year]. [Fills in timeline]. . . . Bronchitis, hospital, [shelter name] [Adds these to timeline]. Ok . . . at the same time, I suppose like a couple of my friends died . . . [by] overdose. Yeah. Like I’ve never done heroin, but apparently it’s like a fickle drug. [Fills in timeline].

Reflection notes written by the interviewer lend support to the rapport-building capacity of timeline mapping. The interviewer noted:

The timeline provided a middle ground, which the participant constructed . . . This allowed the researcher and participant to reach some sort of working consensus on the ground to be covered in the interview, and acted as a reminder to both of how the interview would proceed. . . . I personally used the timeline to jog my memory of previously mentioned items in the interview to be expanded on.

The interviewer found that the timeline acted as an external mediating object through which the interviewer and participant could interact. The physical presence of the timeline decreased the interviewer’s “need for note taking... [and] increased [her] capacity to pay direct attention to the participant and to prevent from distracting them.”

5.2 Theme 2: Participant as Navigators

The creation of timelines facilitated active engagement of participants through *reflection* on major life events and through *visual aspects* by drawing these events on paper. Reflecting on and recalling life events through timeline mapping allowed

participants to create a sense of direction in terms of what they felt comfortable or able to share when asked the interview questions. For example, during an interview, a participant used the timeline to create boundaries around what she could contribute to the interview:

Interviewer: How long were you living with your dad? When did you move out with your grandparents?

Mona: [I was] too young to remember the year and too young to remember anything, so, I wouldn't be able to help with anything around here. [Points to flat line at beginning of timeline].

In this way, the visual aspects of the timeline acted as a navigational filter for participants. To begin with, participants themselves identified which events were significant enough to be added to the timeline. Then, they were able to separate positive and negative events using spikes or dips in the continuous-line timeline, and columns and dates in the list-like timeline. Some participants also expressed emotions by adding emoticons and small diagrams for particular life events. Through such visual distinction of life events, participants were able to preemptively choose what they were comfortable talking about, and with this had the opportunity to exercise more control in directing the interview. This finding was also supported by interviewer reflection notes (e.g., see the reflection note provided above in the section on Theme 1).

5.3 Theme 3: Therapeutic Moments and Positive Closure

The timelines created opportunities for participants to experience therapeutic moments in the interview. Such moments were facilitated by the *dual focus* of timelines on positive and negative events, as well as by the addition of a *future timeline* by participants towards the end of the interview.

The dual focus of timelines on both positive and negative events highlighted by participants helped to maintain participant emotional comfort and calmness within the interview by reducing stimulation of distress about traumatic experiences. For example, in referring to his timeline, one participant described the simultaneity of positive and negative experiences:

This year [was] up and down [pointing to timeline]. Like good, but [I also experienced the] biggest low [because I was a victim of] violence. Because I had [created an art] exhibition on the hate and the violence on the street. And [one week later] I was [a] victim of same violence... I do an [art] exhibition... but at the same time that [violence] happen to you. (Angelo)

This dual focus of the timelines, particularly in combination with the topic-shift strategy described above (see Theme 1), allowed for the interviewer to redirect the participant toward reflections on more positive experiences if a participant seemed “stuck” on discussing difficult events, thereby minimizing emotional distress.

It is important to note that the topic of resiliency in this study was fundamental to minimizing potentially distressing emotional impacts of the timeline mapping process and interview upon participants. Regarding the role of a resilience focus in this research project with marginalized groups, the interviewer commented:

The timeline represents a picture of the lifecourse with which [participants are] confronted at the end of the interview. If the focus of the interview had solely been on negative experiences, such a representation of trauma and setbacks, this would do little to provide positive closure in the interview ... when using the timeline, especially with vulnerable populations, it may be unethical and cause undue harm if the tool is used to explore only negative experiences.

In the second stage of timeline mapping, participants were asked to think about their aspirations and goals for the future. Some of them added a future timeline and this generally facilitated positive closure of the interview. For example, in one future timeline, a participant identified her immediate goals followed by her long-term dream:

So, I think that I've just come to terms with accepting being in school and that a career takes long ... I'm just taking it a year at a time. But I know by the time I'm thirty I'd like to have things like my own home. (Leanne)

The interviewer noted that participants appeared to find the process of “concretely lay[ing] out their future plans on a piece of paper to visualize their future” to be therapeutic, and this “created an uplifting emotional shift that provided a sense of closure for both interviewer and participant.”

At the same time, the interviewer found that participant's use of future timelines was related to their fears of experiencing a future characterized by ongoing (or escalating) violence and socioeconomic marginality. Some participants found the future timeline difficult to envision because they did not want to “think too far ahead ... and be set up for failure” (Christopher), or they wanted to focus on the “most simple things” in the present (Angelo). The interviewer thus noted that the implementation of a future timeline component in the mapping process may produce “feelings of ambivalence, uncertainty, and fears of failure” for some participants and indicated that future timelines need to be used with sensitivity.

6 What We Have Learnt

Methodological literature which explicitly addresses participant-generated imagery in the form of diagramming methods (e.g., drawings, sketches, or outlines) remains in short supply (Jackson 2012). This study contributes to the limited literature on participant-generated timeline mapping through its unique approach of examining multiple sources of data (i.e., timelines, verbal interviews, interviewer reflection notes, and a short socio-demographic survey) and a team-based approach wherein team members discussed and came to agreement on a thematic coding scheme and

analysis. Timelines have been found to strengthen data by enhancing interviewer-participant rapport, mutual understanding, and reflexivity through interactive and supportive engagement with a time-lined representation of a participant's life (Berends 2011; Sheridan et al. 2011; Jackson 2012). Although interviews that involve only one point of research contact with each participant (i.e., one-time interviews) limit researcher engagement with participants and so may pose difficulties for building rapport, such an approach may be necessary as a result of issues of confidentiality (i.e., preserving anonymity), with maintaining contact with mobile or transient populations (e.g., street-involved youth), or because of limited study finances. Our findings indicate that timeline implementation need not be limited to repeat interviews in order to be effective: self-disclosure and interactivity through timelines created a common ground between participants and interviewers, increasing the comfort of participants, and thereby enhanced rapport.

The study findings show that timelines help to focus a participant's attention on the interview by acting as both a memory aid and a visual guide for how the interview will progress, as well as to situate responses within personal and structural contexts while highlighting important events in an individual's life story. That is, the timeline creates a visual middle ground between interviewer and participant from which both can draw to iteratively inform interview questions and responses. In this study, strategies such as the topic-shift were used by the interviewer to ensure that the interview could stay focused on the aim of the study, to move the interview along to meet time constraints, and to ensure minimal emotional distress by redirecting focus when participants appeared to feel distressed. Participants' navigation of the interview was facilitated through their reflection on life events, which encouraged a focus on time-lined event points and allowed participants to walk the interviewer down the path they had illustrated. The timeline also provided a flexible, creative, and collaborative space for communication of meaning, struggle, emotions, and experience through visual aspects. Others have recognized the timeline as a tool to organize and accumulate data, helping to place the research construct in the context of a participant's life events (Berends 2011). Complementary aspects of timelines for enhancement of verbal interviewing are also confirmed by other research utilizing visual methods (Bagnoli 2009; Patterson et al. 2012; Sheridan et al. 2011).

Navigating trauma and emotional distress should be a primary concern for researchers who explore emotionally sensitive topics, particularly when interviewing people who have experienced extensive marginalization. To allow participants to share difficult experiences in a manner that does not cause prolonged emotional distress, an interview approach that fosters a safe and supportive space is necessary for participants to disclose sensitive stories (Goodrum and Keys 2007). Therapeutic aspects built in to the data collection method can help participants address the stress of discussing a difficult or traumatic experience (Horsfall and Titchen 2009; Osei-Kofi 2013). To create a supportive interview space, we relied on the timelines to maintain a focus on resiliency in a context of marginalization and to guide participants to discussing other topics if they appeared to become distressed. Adding a future timeline provided a point of projection that allowed the researchers to consider the possibilities that participants saw for themselves, at the same time

that it operated as a goal-setting tool to facilitate positive closure. However, it is important to note that taking resilience as the topic of investigation allowed the timeline to be an overall reflection of achievements and coping strategies, rather than a confrontation of the participant with their perceived failures and negative experiences; that is, on their own, timelines do not ensure positive closure. Thus, in the current study, the use of visual methods is not assumed to be emancipatory simply because the mode of expression and communication is expanded to non-verbal data, but because such methods should arise as the result of a reflexive research process that maintains awareness and critical engagement with issues of power and representation (e.g., Horsfall and Titchen 2009; Mason and Davies 2009; Osei-Kofi 2013).

In this exploration of marginalization and resilience, timelines can be interpreted as providing lifecourse imagery that is representational of intersections of social structure and individual experience. Although a detailed analysis of this kind is beyond the scope of this chapter, a constructivist approach to lifecourse analysis is conducive to exploring how lifecourse imagery is itself used by participants to construct their experiences in developmental terms, and how this imagery provides insight into the ways that participants make sense of, and position the relative importance of, various events in navigating the struggles they face arising from marginalization and violence (Holstein and Gubrium 2000). The different temporal logics evidenced by the timelines in this study (e.g., use of lists, directions of lines, and the use of spirals or diverging lines to illustrate multiple potential future trajectories) are one example of how constructionist approaches to lifecourse analysis provide an avenue for researchers to better grasp the ways that participants establish the relevance and meaning of particular events for how they experience the present and understand possibilities for the future.

Other contributions of participant-generated timeline mapping include capacity for triangulation of data. The sequencing of events in the form of timelines can aid participants in recollecting personal events and can thereby facilitate more accurate and holistic researcher understanding of a participant's life story – an understanding that may be particularly difficult to develop through one-time ask-and-answer verbal interviews (Bagnoli 2009; Jackson 2012). Further, because participants exercised direct control over the visual representation of important life experiences in the form of timeline mapping and then verbally explained these maps to the interviewer, this decreased the risk of misinterpretation of participants' stories and so allowed for enhanced trustworthiness and validity of the analysis (Karnieli-Miller et al. 2009). In addition, analysis of interviewer reflection notes acted as a component of data triangulation because these notes allowed for insight into the reflexive process of evaluating the implementation of timelines. Interviewer reflection notes also provided insight into how timelines and verbal interviews inform one another and made visible the research process through the eyes of the interviewer.

The critical emancipatory and feminist approach of this project guided our interest in using the timeline to act as a middle ground between the interviewer and participant, giving marginalized participants a voice through nonconventional forms of communication, as well as through their increased control in directing the

interview. This research approach, in combination with a focus on resilience, resulted in highlighting the strengths of street-involved youth, as well as in exploring the multifaceted coping strategies they engage in, thereby moving beyond much extant research which remains restricted to documenting the marginalization, victimization, and deviance of street-involved persons. Under a critical emancipatory and feminist approach, it was important for the research team to give back to the community of participants and to debrief participants to ensure no harm. As such, access to counseling was provided post interview to ensure that any prolonged distress that may have arisen as a result of the interview process could be addressed. Further, participants were encouraged to debrief with counselors or the co-coordinators of the collaborating agency serving street-involved youth if they wished to do so, and to contact researchers if they had any questions regarding the project outcomes. Upon research completion, researchers disseminated results in a newsletter designed for street-involved youth and met with agency employees to provide a question and answer session regarding the research process and outcomes (for more information on post-research engagement with participants and the collaborating agency, see Kolar et al. 2012). In order to encourage the timeline being seen as a creative and self-exploratory project by participants, we suggest that researchers create a copy of the timelines for analysis and provide original timelines to participants. However, this is only possible if the research is conducted with persons who will be seen on more than one occasion, or in the case of one-time interviews such as our own, where copying or scanning facilities are available.

7 Conclusion and Future Directions

It cannot be overemphasized how central the topics of investigation and selection of research approaches are for informing the implementation and analysis of timeline mapping. On their own, timelines do not inherently provide a more equitable research medium. Rather, as illustrated in this chapter, timelines hold this potential when mobilized with particular goals in mind, including managing and maintaining awareness of power relationships between interviewers and participants, and engaging in issues of representation and voice for marginalized groups. Similarly, the resilience focus in the overarching project facilitated the expression and documentation of experiences of nonconventional coping and achievement for participants through the use of timelines and verbal interviews; without this resilience focus, the use of timelines does not necessarily provide positive closure. When combined with power-conscious epistemologies and a research focus that facilitates critical engagement with the representation of experiences of coping and success of marginalized groups, timeline methods may greatly supplement investigation of complex constructs through a life-story approach, the use of visual aspects, and increased participant control of the interview.

Two limitations need be mentioned here. First, we have made clear that this study is limited to application in one-time interviews; experiences of and issues with implementing timelines in repeat interviewing may differ. Second, this study

examined the integration of timelines with qualitative interviews specifically with street-involved youth. Readers should not assume that the advantages and issues explored in this chapter apply equally to all groups (e.g., see Kolar et al. 2015 and Ahmad et al. 2013 on differences in timeline implementation and participant experiences between street-involved youth and South Asian immigrant women who have experienced domestic violence). This study was not intended to be automatically transferable to diverse groups, but to inform readers and researchers who are considering using timelines in their own work of issues for consideration. For instance, more involved coaching of participants through their mapping of timelines may be required for participants who are unfamiliar or uncomfortable with visual modes of expression in order to decrease their discomfort and uncertainty, and thereby enhance engagement. The implementation of timelines should thus include consideration of participants' levels of familiarity with visual methods, as some groups may require more involved coaching in order to more effectively engage with timeline methods.

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Capturing the Research Journey: A Feminist Application of Bakhtin to Examine Eating Disorders and Child Sexual Abuse

118

Lisa Hodge

Contents

1	Introduction	2062
2	A Feminist Approach to Bakhtin's Dialogism	2063
3	Bakhtin's Authoritative and Internally Persuasive Discourse	2065
4	The Study: Situating the Context	2066
5	Narrative Bio-sketches	2066
5.1	Analiese	2067
5.2	Ollie	2067
6	Dialogical Semistructured Interviews	2068
7	Poetry as Part of a Layered Account	2071
8	Visual Methods as Another Layer	2072
9	Conclusion and Future Directions	2075
	References	2076

Abstract

Important links have been established between eating disorders and child sexual abuse. These medical and positive studies, however, have causally quantified the link, and analysis has remained within the parameters of individual psychology. Thus, women's perspectives and experiences are ignored. In this chapter, I argue for a feminist application of Mikhail Bakhtin's sociological linguistics when examining women's experiences of eating disorders and child sexual abuse and the links between them. Bakhtin's theoretical constructs – authoritative and internally persuasive discourse – can enable researchers to expose the seemingly objective *truths* that overshadow alternative discourses competing for expression. I also argue for the use of a *layered account*, a technique that enables me to incorporate artistic expression. This chapter begins with an overview of how

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Bakhtin's theoretical constructs can promote a feminist paradigm for analyzing women's understandings. Drawing from my research that examined the nature of the relationship between women's experiences of child sexual abuse and eating disorders, I demonstrate how Bakhtin's theoretical constructs can expose the hidden mechanisms of control found in these gender-based oppressive practices. I also illustrate how drawing and poetry, when used in qualitative research methodologies, can create space for interactional discovery and give voice to the unspeakable.

Keywords

Bakhtin · Sociological linguistics · Feminist paradigm · Women · Eating disorder · Child sexual abuse · Drawing · Poetry

1 Introduction

My previous work as a social worker at the Eating Disorders Association of South Australia provided the impetus for the doctoral research upon which this chapter is based. I use the blanket term *eating disorders* throughout this chapter because I have found, as have others, that, despite common assumptions, anorexia and bulimia do not necessarily exist independently of each other, as oppositional categories (e.g., see Burns 2004; Warin 2004). Anorexia and bulimia are practices commonly engaged in either sequentially or simultaneously. Like Burns (2004), I push for a notion of fluidity between the eating disorders and the importance of challenging the way in which we have become accustomed to thinking about the categories of anorexia and bulimia that privileges anorexia above other types of eating distress.

I was driven to examine the link between eating disorders and child sexual abuse, because I found it to be an under-explored area in feminist research. Feminist scholars had acknowledged the significance of child sexual abuse in the backgrounds of women with eating disorders (see Wooley 1994; Malson 1998; Bordo 2003; Warin 2010). Yet, feminist research had not focused on women who had experienced both. Medical and positivist studies had causally quantified the link between eating disorders and child sexual abuse (Smolak and Muren 2002; Sanci et al. 2008; Chen et al. 2010). Although significant in naming the link, these studies portrayed women in pathologizing ways and ignored women's perspectives and experiences. The problem with quantitative approaches is that pathologized accounts of women frame them as victims; they are stigmatized and silenced, and the problem becomes worse.

It was *not* the aim of my research to suggest that all eating disorders in women are a direct result of sexual trauma. However, child sexual abuse is frequently an influencing factor and can no longer be ignored when understanding eating disorders and how women recover. Central to the study was the question of gender, as child sexual abuse and eating disorders are argued to be two highly gendered phenomena. For example, the majority of individuals affected by eating disorders are women (Malson and Burns 2009), and this is also the case with child sexual abuse victims

(Warner 2009; Stoltenborgh et al. 2011). The vast majority of child sexual abuse perpetrators are male with females comprising only 1–4% of all sexual offenders (Peter 2009). Despite child sexual abuse being a criminal offense, perpetrators are often portrayed as normal men who have been seduced by a precocious child or forced into the abusive behavior by an inadequate wife/mother (Hooper 1992; Bolen 2001). Moreover, child sexual abuse is conceptualized in medical terms as resulting in permanent damage to the personality (Warner 2009). Within this view, women are depicted as being made ill through their experience. This is also common in eating disorder theorizations, which is one example of how these experiences are similarly gendered in some respects.

As medicine has “owned” the study of the body and its disorders since the seventeenth century (Lafrance and McKenzie-Mohr 2013), dominant medical discourse portrays eating disorders as personal and internal problems of biochemical irregularities or internal psychological maladjustment (Malson and Burns 2009). Rather than positioning eating disorders within a framework in which analysis remains within the parameters of individual psychology, this chapter shifts the focus from “a damaged personality” to an eating disorder being “an understandable response” to sexual trauma. Indeed, the women who participated in my study articulated and understood eating disorders in a multiplicity of ways. Eating disorders were constructed as self-punishing and self-destructive, yet simultaneously self-producing. In response, I examined the social and structural constraints on the women and how their eating disorders could be viewed as an extreme way to “cope” with child sexual abuse.

As women feel and think about the social world through the body, a body which is not independent of social relations, but continuously constituted by them (Kleinman et al. 1997; Yang et al. 2007), emotions can illuminate aspects of women’s experiences and add power in understanding, analysis, and interpretation. Thus, emotions, which are understood in this chapter to be products of both the body and discourse, offer valuable insights into social relations and social dynamics (Probyn 2005). Yet, not everything can be realized in language. The chapter also demonstrates how artistic processes can give participants a voice to resist with. Artistic forms can provide a different window into the lives of participants (Clarke et al. 2005) and enable the expression of powerful emotions that might not always be easily expressed in a clear or linear fashion (Furman 2006a). In this way, the theoretical and methodological framework for this research project grew out of the desire to counter silence and make women’s “invisible inner thought, vision, or experience visible” (Ramm 2005, p. 66).

2 A Feminist Approach to Bakhtin’s Dialogism

As language is inevitably distilled with culturally ingrained, authoritative discourses, it was important to understand *how* meaning production is bound by the larger relevant discourses in which meanings are produced. As such, I turned, in part, to Russian philosopher Mikhail Bakhtin’s (1895–1975) sociological linguistics, for a

theoretical framework. Bakhtin (1981) developed, over a prolific career of some 50 years, a theory known as *dialogism*, in which he conceived of all discourse as dialogical. Bakhtin argues that there is no one interpretation, no single harmonious worldview, and no single truth (Bakhtin 1981). Communicative acts only have meaning in particular situations or contexts. Bakhtin (1981, p. 276) writes:

Any concrete discourse (utterance) finds the object at which it was directed already as it were overlain with qualifications, open to dispute, charged with value, already enveloped in an obscuring mist-or, on the contrary, by the 'light' of alien words that have already been spoken about it. It is entangled, shot through with shared thoughts, points of view, alien value judgements and accents. The word, directed toward its object, enters a dialogically agitated and tension-filled environment of alien words, value judgements and accents, weaves in and out of complex interrelationships, merges with some, recoils from others, intersects with yet a third group: and all this may crucially shape discourse.

What Bakhtin is suggesting here is that we do not learn words from a dictionary, we acquire them from hearing or reading the words of others and, therefore, they are marked with the voices of those prior contexts. (Bakhtin 1986)

I used Bakhtin's rich body of theories as both as a methodological tool when conducting interviews and as a theoretical lens when analyzing the interview transcripts. In adopting a Bakhtinian perspective toward interviewing, I understood that no voice exists in isolation but is shaped by, relates to, and competes with other voices. In this sense, the dialogical interviews were regarded as a joint project where meanings were mutually constructed between the women and me. Communication was seen as an interactive process where the women were encouraged to be active agents through reflective processes. This included the use of specific questions that instigated self-reflections (Frank 2005) and me showing each of the women the analysis of her interview. In this way, dominant discourses that held binding authority within the women's narratives could be overturned together, and other discourses that were competing for expression could be exposed and analyzed within subsequent interviews. By inviting the women to participate in the deconstruction of their own experience as acts of engagement with me, the roles of researcher and participant were destabilized, and my own voice, perspectives, narrative, and knowledge were intertwined with theirs (see also ► [Chap. 119, "Feminist Dilemmas in Researching Women's Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise"](#)).

Yet, like almost all literary critics in the first half of the last century, Bakhtin does not include women as authors or speakers in his discussion of literature. Bakhtin's socially and historically grounded concept of language does, however, lend itself to feminist criticism because he recognizes that literature exists in a political context by taking into account the various determining social and historical factors of language. A gender-aware application of Bakhtin can disrupt patriarchal language and explore marginal voices within dominant discourses (Bauer and McKinstry 1991). As such, a Bakhtinian theoretical framework enabled me to illuminate multiple meanings by providing a strategy for resisting hierarchical and normalizing discourses. Through a feminist application of Bakhtin, I was able to consider the contradictions within discourses and the

multiple ways in which women negotiate *how* eating disorders, as a practice, work “across multiple planes” (Probyn 1987, p. 210). Interrogating the dominant discourses that emerged in the women’s narratives gave voice to their rarely discussed experiences and provided the opportunity for powerful counter-narratives to established hegemonies to emerge and psychiatric and biomedical discourses to be challenged.

3 Bakhtin’s Authoritative and Internally Persuasive Discourse

To understand the embodiment of women’s experiences of child sexual abuse and eating disorders, I used Bakhtin’s key concepts, *authoritative discourse* and *internally persuasive discourse*. These two theoretical constructs described in Bakhtin’s *Discourse in the Novel* inform my analysis and promote a feminist agenda (1981). Bakhtin contends that consciousness is a process of interaction among authoritative and internally persuasive discourses; the self is, therefore, an event of language experience. Moreover, the body is defined by those with an authoritative voice of what is the “truth” of human nature. Through the use of Bakhtin’s theoretical concepts, I am able to remain attuned to how power works in the process of communicating with the women I interviewed. Understanding the social, political, and historical implications of words passing through a speaker on their way to a listener is critical to understanding how different discourses compete with a single utterance (Alcoff 2008). I drew on Bakhtin’s notion of the authoritative and internally persuasive discourse to expose seemingly objective truths in the women’s narratives that overshadowed alternative discourses competing for expression. An authoritative discourse has such binding authority that it seems untouchable, inspiring only adoration and respect, and it maintains the status quo. In contrast, an internally persuasive discourse is denied all privilege, as it is “frequently not even acknowledged in society” (Bakhtin 1981, p. 342). Where an authoritative discourse is weighted with authority and appears to remain within a single language system, an internally persuasive discourse is open and unfinished (Bakhtin 1981).

Bakhtin (1981) argues that when reading a text authoritatively, a seemingly objective truth about the meaning of that text is established. From this position, authoritative discourses are complicit with patriarchal ideology. This is a dangerous prospect for women, as male truths are spoken with such power that their assumptions are no longer questioned. A prominent example of an authoritative discourse is the medical discourse of eating disorders. Medical discourses pathologize the experiences of women and, as such, minimize attention to possibilities for recovery (Becker 2010). Searching for alternative discourses in the women’s narratives offered the opportunity to incite struggle and encourage creativity. As meaning is produced (or policed) through discourse, rather than revealed through it (Burr 2007), these concepts enabled me to examine how gendered and disciplinary discourses created and sustained the women’s eating disorders.

4 The Study: Situating the Context

I conducted multiple semistructured qualitative interviews with seven women who had an eating disorder and had experienced child sexual abuse; my aim was to create a “living dialogue” in which authoritative discourses could be teased out and disrupted (Francis 2012, p. 5). To recruit participants, colored flyers asking participants to volunteer for the study were placed around the University where I undertook my PhD in South Australia. The flyers asked women to volunteer for the study who were 18 years or older and who self-identified as having an eating disorder and unwanted sexual experiences in their past. The flyers also stated that participants were required to participate in multiple interviews. As child sexual abuse is considered by radical feminists to be a manifestation of the oppression of women, inherent in a patriarchal society, both the causes and consequences can be markedly different depending on one’s gender (Reavey and Gough 2000). Thus, I chose to focus on experiences of women, and therefore only women were recruited. Seven women were recruited and each participant was interviewed up to five times. The point at which the data reached saturation point determined the number of interviews conducted with each woman. I planned to recruit more participants if I had found this not to be the case when analyzing the data; however, no further recruitment was required.

Potential participants who had seen a flyer and chose to contact me were given a verbal description of the study as well as a written information sheet. The information sheet contained details about the study’s aims, processes, and confidentiality, and it outlined how potential participants could participate and provided contact details of the researcher and the university’s Human Research Ethics Committee. Participants were provided with a second information sheet and verbal description if they wanted to include their artwork, poetry, and journals, which clearly explained the use, collection, storage, dissemination, and future use of the artwork, poetry, and journals. The women signed consent forms before participating in this research: one to participate in the interviews and a second form prior to their artwork, poetry, and journals being collected.

This research involved individual interviews averaging 90 min each in duration, which were digitally audiotaped and then transcribed *verbatim*. Interview participants were asked to self-select fictitious names at the start of the first interview. During transcription of interviews, any identifying features were deleted and fictitious details inserted in order to ensure confidentiality. These fictitious details were sustained through data analysis and reporting of outcomes. I asked the women to talk in detail about their understanding of their experience.

5 Narrative Bio-sketches

This next section introduces the reader to two of the seven women who constituted the sample of this research by providing a compressed narrative bio-sketch (as appropriated by Berger 2006) for each woman. Following Berger’s (2006) approach in her study of HIV-infected women drug users, the narrative bio-sketches presented here lay the groundwork for understanding the context of the women’s lives. They

show snippets of how the women talked about their experience of an eating disorder and their experience of child sexual abuse.

5.1 Analiese

Analiese was a 24-year-old woman who had an older brother who lived interstate and parents who were professionals. She saw her “mum a fair bit” but did not have a lot to do with her father. Her parents would frequently “split up and get back together and split up.” Analiese told her mother that she would move out if her father came back home again, and so, with 24 h’ notice, Analiese found herself “homeless for about 12 months.” Analiese said that she had “dissociative identity disorder” which was diagnosed “about 4 or 5 years ago,” and she considered this to be “a post-trauma related condition where basically different personalities develop.” Analiese had had “ongoing contact with the Mental Health Services” since she was about 12 or 13 years old, “not really knowing what’s going on.” She spent most of her high school years “in and out of hospital” and that this was for “the eating disorder stuff and depression and suicide attempts.”

Analiese was diagnosed with anorexia or what was described “as anorexia in the DSM.” She “had big issues with vomiting,” so she could never vomit up her food but that she “would exercise.” She said “there was a lot of sexual abuse” in her childhood and that she “basically grew up in the child sex industry” being “used in the production of pornography” from “2 years old” until she was a teenager, when she “rebelled against everything and left and ran away from home.” Very quickly, Analiese realized that the only way she really knew how to survive was to work in the “sex industry.”

Analiese “did a lot of stuff as a kid,” like “self-harming” and “took a lot of drugs, did a lot of the normal feral kid stuff but probably a lot more mass extreme.” Part of her eating disorder was “probably related to that.” When she was first hospitalized for anorexia at 14 or 15, when they were trying to get her to eat, she felt she did not “deserve food.” She had to battle the negative effects of the “psych meds” that made her keep on the weight and that her “obsession” with numbers and getting to a certain weight started after that. Analiese said her parents had “a lot of denial that there was an issue” and that they would not allow her to “see a psychiatrist or psychologist,” so she accessed services at “Second Storey” because she could access them “without parental consent.” When her father found her medication in her room, he became extremely angry and threw her “across the room.” Analiese said her mum is very supportive now and that “she knows what DID [dissociative identity disorder] is, where it comes from, and she still won’t ask anything.” Analiese is no longer “skinny enough to be diagnosed with anorexia” but that she still has “a lot of the behaviors.”

5.2 Ollie

When I first interviewed Ollie, she was a 26-year-old woman who had two older brothers and was raised in a practicing Christian family where she “had to be a Christian” and “had to be well behaved” and act like a “little 50s housewife.” She

“was molested by a babysitter at 3.” She said she “was raped at 4” and that she understood this to have been “my father” for an unknown period of time and was then raped at 17 by a boyfriend. Ollie always believed that she was “never going to be as good as anybody else at any given thing”; she was “never going to be as beautiful” or was “never going to be as valued as anybody else.” She understood that her “worth was so much less” because she had “been ruined by something.” Ollie had no memory of her childhood – it was “blank.” She started having flashbacks or memories at different stages although she had “always just put them down to nightmares or day mares.” At the age of 19, Ollie “started asking questions”; she started experiencing memories that were “almost like body memories” saying that she could “almost feel it happening at times.” Ollie was depressed until she “started having flashbacks.” Now, instead of feeling really depressed, she felt “shame” that it was her “fault” and that she was “disgusting” and “no-one’s ever going to want that.” At age 4, Ollie woke up one morning to find that she had a “double inguinal hernia” which she explained was “caused by severe trauma.” She had to have surgery to stitch all her “muscles back together.”

Ollie described having the eating disorder “since probably 9 or 10 years old” and went on to say that her “negative attitude towards food” tied “into a really negative body image and self-image,” and the two were “linked somehow to the abuse.” Ollie said the eating disorder “wasn’t so much a cry for help”; it was more about if she was treated badly, it was her “weapon” as it made her feel like she “had some power too.”

Her father “used to bait” her “in front of the family,” and it would get to the point where she avoided him as she “couldn’t trust him” and “did not feel safe.” When he came within a meter of her, she “already felt violated in some way” not because she “knew that something had happened before” but because he made her “feel dirty.” At about 14 or 15, she started self-harming as a way of “releasing stuff” that was happening in her family and because she believed that she “deserved to feel pain on a regular basis.” Ollie said self-harming was a “coping mechanism” that she used to help her cope with emotions or anything that made her “feel out of control” and that it was “a punishment too.” Ollie also said “the limitation of food was another coping mechanism” for her and went on to say that, by starving, she could “get to control” of one area of her life and that she was rewarded for it by “getting thinner.” Ollie always felt guilty about eating, no matter how much she ate, and would always go to bed feeling “dirty and heavy.” She said she felt she was the issue and that “the abuse left its dirty paw prints” all over her, and if she made herself smaller through starving, she was “making the mess smaller.” It was also important for Ollie to have structure and order and that she needed to “have a plan,” because having a plan was “another aspect of the control.” She said that “without a plan all the things” that she had been running from would “finally catch up.”

6 Dialogical Semistructured Interviews

Following a dialogical method, which considers verbal responses to be “themselves built on responses to historic utterances made by ourselves and others” (Francis 2012, p. 4), I conducted multiple, individual, semistructured, face-to-face interviews

with Analiese and Ollie. Conducting more than one interview with each woman enabled discourses to be built on or resisted. A distinguishing feature of dialogic research is including oneself as an active participant in the narrative and its interpretation (Riessman 2008; see also ► Chap. 24, “Narrative Research”). In these dialogical interviews, my communication with the women was not approached from the point of view of transmission of information but was seen as an interactive process in which both speaker and listener played an active role (Lahteenmaki 1998).

The interviews were conducted in a place of the women’s choosing, where they felt most comfortable and at a time that suited them. I conducted the interviews over a 12-month period to allow time to transcribe *verbatim* and analyze each interview before conducting subsequent interviews with each woman. After each interview, I analyzed the transcripts using a thematic analysis (Patton 2015; see also ► Chap. 48, “Thematic Analysis”). After each interview with each woman, and before conducting further interviews with her, a copy of her interview transcript was offered to her.

When undertaking the multiple interviews with each participant, the research process became a dialogue between the researcher and participant. In a similar way to Lather and Smithies (1997, p. xvi), I wanted to position “the reader as thinker, willing to trouble easily the understood and the taken-for-granted.” Thus, the more room that I made “for the voices, language, and moving stories of the women’s lives,” I hoped, the more engaged the readers would be in the analysis (Abma 2002, p. 25). This is because, if the text refers to the reader’s own lifeworld and they can connect their experiences with the text, additional meaning can be gained from it (Abma 2002). As such, I present large amounts of the women’s interview transcripts.

I used Bakhtin’s understandings to tease out the discourses that inform both the speaking and hearing integral to the construction of each theme. As Bakhtin (1981, p. 282) insists, “understanding comes to fruition only in the response.” Prior to conducting further interviews with each woman, I showed her my written analysis containing the emerging themes and her quotes that were used to determine these themes. New interview questions were designed, and subsequent interviews were conducted after each woman had the opportunity to comment on my interpretations of her interview. This process was repeated for each interview. As a dialogical researcher, I was more than an observer of the women’s lives outside the interview; I participated in acts of engagement with them in understanding that their stories were the site of struggles permeated by multiple voices, how each voice was the site of multiple voices, and what was the contest among these voices.

Figure 1 provides an overview of the dialogical process between the women and me. Figure 1 shows, at a glance, the first layer in the analysis.

There was potential for conflict between my feminist dialogic frame of reference and the women’s interpretations, as I tried to explain their lives without violating their reality. However, from a Bakhtinian view, meanings are negotiated. Each woman and I did our best to arrive at a compromise regarding our interpretations. Lahteenmaki (1998, p. 91) suggests

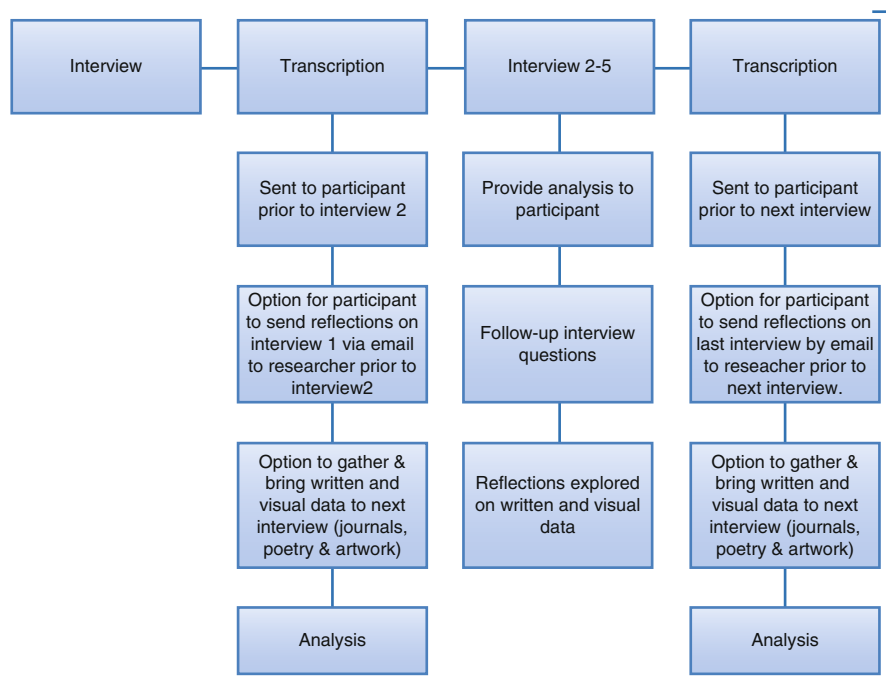


Fig. 1 Creating layered accounts through the dialogical interview process

Communication always includes ... an element of struggle over meanings ... it must be borne in mind that absolute disagreement is also impossible in the sense that, in order to disagree on something with someone, there naturally has to be a common ground mutually shared by both parties.

Thus, the dialogical process opens up quite different assumptions about the creation and meaning of truth and knowledge (Riessman 2008). This is particularly important for research on child sexual abuse and eating disorders where hegemonic discourses can conceal the potential for other understandings and thereby the potential for resisting silenced trauma.

As I did not want to passively record where each woman was in her life, I used specific questions that were developed from the emerging themes to instigate self-reflections with each woman. Thus, the women actively coauthored, or co-constructed, in this dialogical process. Multiple meanings were negotiated, and workings of power were acknowledged and analyzed together. This method of conveying information fitted with my feminist agenda, as it allowed the women to determine at least some of the terms by which they would be known.

The women's written and visual data was also used to help engage the women in talk. Using an adaption of Rose's (2008) framework as a guide (see Hodge 2014), I asked Analiese to explain the meaning of her drawing and the metaphors Ollie used in her poem. When the interviews were transcribed and analyzed, I could go back to

the women with their poetry and drawing and use my analysis to instigate further questions. Ollie and Analiese then had the opportunity to critically reflect and expand on the meanings of their poem and drawing after discursive themes had emerged in my analysis. Thus, the interviews were fluid, and their structure was determined to a large extent by the women.

7 Poetry as Part of a Layered Account

Creative writing is used as an avenue for expressing feelings and emotions, which is considered easier than through talk. Poems are a powerful narrative tool which can further empathize and understand, as poems speak “in a unique way from the interior of human experience in a way that science can never” do (Shapiro 2004, p. 172). Thus, poems have been argued to better represent the speaker and are compelling research revelations in their own right (Lahman et al. 2010). The use of poetry in this study offered a different window into the lives of participants (Clarke et al. 2005), because what was included in the poem was just as important as what was left out of it (Poindexter 2003). Poetry opened up possibilities for discovering new meanings as it allowed the women to critically reflect on experience, with at least some of the habitual meanings held in abeyance (Oiler 1983). This critical reflection offered space to voice-silenced traumas.

Poetry, as a source of data, fitted well with the dialogical interviews. This is because it is less linear than other texts (Gannon 2001). It is in the pauses and gaps and motion that readers can insert their own lived experience and their “various selves to create embodied knowledges” (Gannon 2001, p. 791). Thus, the women’s poetry was used in a reciprocal relationship in which insights and meanings were developed and shared (Furman 2006b). One way to mitigate the richness of differing meanings within a single poem is to encourage full inclusion of the text, allowing readers “to act as triangulated investigators” (Shapiro 2004, p. 175). As such readers can vicariously enter into Ollie’s lived experience, in a way that is not available in other modes of writing/research.

Ollie said that using poetry to talk about her experiences of child sexual abuse and an eating disorder was a positive experience, as it offered another layer of understanding and a way to give voice to unarticulated experiences. Child sexual abuse is often difficult to speak of directly, and for Ollie, poetry was a means to effectively convey powerful and complex emotion. As Furnam (2004, p. 163) contends, poems transcend the limits of language and provide in-depth understanding of lived experience “operating on the level of image, the poem resounds in the mind.” Unlike other forms of expression, for Ollie, words, space, and sound merged, and this was critical to the articulation of meaning. Poetry opened a space for Ollie that was “attentive to multiple meanings” and more easily enabled the accessing of subjugated perspectives (Leavy 2009, p. 64). As Leavy (2009) points out, listeners and readers tend to be moved by the power of poetry, and the impact of a metaphor was more powerful than if Ollie had merely described her experience. Ollie used poetry to represent the essence of what she wanted to say in a vivid, sensory way.

In *Ollie's Poem*, she has used forceful words such as “raped,” “miracle,” and “freedom” and phrases including “in my normal voice,” “when I cut myself,” and “I want to kill myself” to express the extent of her emotional turmoil and her feelings, in which she was metaphorically dead and alive at the same time.

Ollie's Poem I want a love that knows no fear. I want to stop ruining what I have. I want a love that even time will lie down and be still for. I want to FEEL. I want to know that I'm worth more than what I weigh. I want to be able to say I'm good at something. And believe it. I want to know why I feel like I've been raped. I want it to be OK when I cut myself, I want scars to be acceptable. I want to be able to say “I love you” in my normal voice. I want a miracle! I want some help! I want to know who I am. I want my own space and freedom. I want to enjoy eating instead of hating it. I want to kill myself, instead of always talking and thinking about it. I want more romance and less sex. I want to want sex.

The repetition of “I want” is strong in how it eludes to a sense of powerlessness. It also creates space for Ollie's own voice in the poem to say what she could not say out loud and in public. In the phrases “I want to stop ruining what I have” and “I want to know that I'm worth more than I weigh,” Ollie connected her feelings of worthlessness to her eating disorder. Ollie's poetry symbolically expressed her fear of being alone in her struggles and her confusion around sexual relationships. Although eating disorders have been portrayed in numerous ways – as a means of avoiding sexual contacts and feelings; as an expression of anger, inflicted upon the woman herself as a form of punishment; as a coping strategy for self-hatred and powerlessness; as posttraumatic stress symptoms related to severe boundary violations; and as a way to make oneself sexually unappealing – for Ollie, an eating disorder was a metaphor for a symbolic relieving of abusive experiences. Ollie's body was the place where knowledge, memory, and the pain of sexual trauma were stored. As the body is integral to the sense of self, discourses of femininity that Ollie had to negotiate rendered the body a trap. Ollie's struggle with her embodied feelings of worthlessness was primarily regulated through shame. An eating disorder was understood as a process of transformation of this emotion through the physical body. Her shame became contained through disordered eating practices and thus made safe. As Lawrence (1984) points out, an eating disorder can affect the relationship between oneself and one's body, and for Ollie an eating disorder was a solution to a problem that she found impossible to deal with any other way. It was painfully difficult to choose to give up, which shows the complexity of her agency. Being able to exercise her agency, I am arguing, provided Ollie with a sense of safety, and thereby was used to negotiate the complexity and ambiguity of sexual relationships in the aftermath of child sexual abuse.

8 Visual Methods as Another Layer

The ability of drawing, to surface unspoken thoughts and feelings, has long been accepted by art therapists (Malchiodi 2007). Therapists have used this tool for many decades to facilitate expressions that are not easily put into words (Malchiodi 2007).

Within psychology, images have traditionally been given the status of a more simplistic form of communication and confined to use with children or those deemed less able to communicate thoughts and feelings (Reavey 2011). Drawing was used in this study as a visual product and a process, offering a way of exploring the multiplicity and complexity that is the base of much social research interested in human experience (Guillemin 2004; see also ► Chap. 101, “Drawing Method and Infant Feeding Practices Among Refugee Women”). Specifically, drawings were used to encourage Analiese to talk about her experiences, affording her every opportunity to frame her own experiences, unencumbered by my biases. This enabled me to collaborate with Analiese, which fitted well with my Bakhtinian dialogic feminist methodological approach.

Some methods for analyzing visual data are suggested to be more methodical than others. They lay down very precise criteria for analysis and a step-by-step procedure. My aim in using visual data was not to obtain an understanding of the participant's drawings. I wanted to understand with the drawings about the life of the participant in this study. In order to *look at* the image and *look behind it*, I drew on Rose's (2008) critical visual framework. According to Rose (2008), the interpretation of visual images exhibit three sites at which meanings of an image are made: the site of production of an image, the site of the image itself, and the site of the audience. I followed Guillemin's (2004) adaption of Rose's framework, where the data comprised both the visual images and the participant's verbal descriptions of the image. It was important to ask Analiese to describe her drawing as an essential part of the method, as it elicited the nature of the drawing and why she chose to draw that particular image. This process instigated critical reflections on how Analiese's artwork represented her experience of child sexual abuse and an eating disorder, and the significance of what she had drawn in relation to her previous statements made during the interview. The events, experiences, and interactions that preceded the drawing all worked to produce the understandings that were embedded in the drawing (Guillemin 2004).

I also left room for readers to interpret the pictures themselves. Radley (2010, p. 268) suggests “that what pictures portray and what stories narrate are better thought of as versions of our experience of the world than as constructions of the world that we experience.” Although the images needed to be contextualized to some degree by words, Rose (2008) argues the actual image itself can be used as evidence to develop and support, or to supplement, research findings. Pink (2001) suggests exploring the relationship between the visual and the social and cultural contexts of knowledge production by using a reflexive approach toward the collation and analysis of visual data, which does not depend on translating visual evidence into verbal knowledge. Thus, the participant's drawings were used to present things that words could not, as “not everything that can be realised in language can also be realised by means of images or vice versa” (Kress and van Leeuwen 1996, p. 17).

Figure 2, a black-and-white drawing, was drawn by Analiese about 7 years ago, and it was one of the first that was specifically about the eating disorder. Here, Analiese's skeletal body is stripped of any facial features, hair, fingers, or clothes suggesting a total lack of power over her life – a facelessness and defenselessness.

Images of demons dominate the picture. Analiese has portrayed herself as running but barely able to stay outside of the grasp of the multiple demons that are attempting to envelope her, further emphasizing an overwhelming sense of powerlessness. As such, this drawing is also full of movement, marked by a moving body running away from the demons. The demons are also in motion, close behind the running body. In this way, Analiese's body is in perpetual motion, her sense of self always on the move, trying to get away from the demons so that they do not overcome her and become part of her own self. In this sense, the embodied self is not static or passive – it is active, even though it responds to the trauma it cannot name easily, or the emotional labor which goes into staying ahead, staying in control. The drawing, I am suggesting, names the emotional effort, the bodily labor, put into staying in control, all of which cannot be named with words but is nevertheless perceived visually.

When I asked Analiese for her reading of Fig. 2, she said it was about controlling her food as a way of running away from her demons and everything that was behind her. Having demons following her was a common theme in her drawings. This was because they represented “the magnitude of emotion” and the inner demons that she developed as a result of feelings of worthlessness. This was significant because later

Fig. 2 Analiese's self-portrait



in the interview, Analiese said she was beaten as a child if she expressed emotion. When I asked Analiese if she connected this picture to the abuse, she said that her “circumstances” were “still very strongly dictated by the abuse.” Even though she tried to distance herself from the experience, there were “triggers” that took her back:

There are probably elements of trying to get away from that and some of the stuff that I’m dealing with now as well as it is about actually accepting that some of my circumstances are still very strongly dictated by the abuse and the main perpetrator of the abuse is still a very powerful person in my life. So I guess it’s almost that bind of you trying to run away from it but they keep up with you. So things like the fact that the perpetrator of the abuse or the main perpetrator is still a very strong person in my life is kind of one of those things that you can’t escape them constantly, they’re following you and there’s all those triggers that kind of take you back. So there’s that and then there’s other things like being in places and stuff that kind of trigger things and all of a sudden you remember stuff and yeah, so everything kicks off. (Analiese)

Bakhtin (1981, p. 401) contends that “all direct meanings and direct expressions are false.” This means that when we seek to understand a word, it is not the direct meaning the word gives to objects and emotions that matters but rather the self-interested use to which this meaning is put and the way it is expressed by the speaker, a use determined by the speaker’s position. Taking Bakhtin’s point into consideration, both Analiese’s narrative and drawing suggest the enormity of her enduring struggle in “trying to run away” from the emotional “stuff” she was trying to deal with. However, she was powerless in the sense that her emotional state was destabilizing and unsettling and constantly evading her attempts to govern it.

9 Conclusion and Future Directions

This chapter has shown that through the internally dialogic quality of discourse, it allows Ollie and Analiese to make connections about their experiences of child sexual abuse and possible influences in later life. The chapter has also shown how the women made sense of their experiences through drawings and poetry, which flowed smoothly as a continuation of the narrative. By incorporating poetry as data, the “commonsense” assumptions of authoritative discourses that “center” women can be ruptured, and internally persuasive discourses about the female body emerge. The women spoke of a loss of control, and they attributed this loss to experiences of child sexual abuse and sexual trauma. They used their bodies to negotiate internally persuasive discourses – that is, alternative positions and voices – to challenge or contradict authoritative discourses of the female body. Drawing and poetry facilitated recall of painful memories, which otherwise might have been difficult to share with others. Controlling their bodies through an eating disorder gave the women a sense of control over their lives, and this was directly related to the control that was lost to them in child sexual abuse.

Trying to be perfect and in control are common in eating disorder theorizations. However, from a Bakhtinian position, there is a different story waiting to be told. The women’s narratives articulated a controlled body that was about more than perfectionism; it was about trying to cope with a loss of control of the body and

emotions and thereby a loss of self that was experienced as part of child sexual abuse. The women's preoccupation starvation functioned as a powerful "normalizing" strategy. As such, getting thin was not about getting thin, per se, but rather, staying in control of their bodies, emotions, memories, and thoughts about the abuse. Put differently, not eating was an assertion of individual control where food and body weight featured as the only arenas in which control was possible. In this sense, as Malson (1998, p. 123) describes, the controlled body quite explicitly signifies total control and "the positive subjectivity signified by the thin body here is accompanied by a subtextual subjectivity of 'failure' in all other aspects of life." Yet, as Bakhtin (1981, p. 348) asserts, "one's own discourse and one's own voice... will sooner or later begin to liberate themselves from the authority of the other's discourse." From this position, disordered eating served as an attempt by the women to stave off the painful effects from their experience of abuse and to manage and expunge feelings and emotions, memories, and thoughts while providing a sense of control through the body. Starving signified having a sense of voice about something they could not talk about openly or freely.

I want to conclude by advocating for two things. First the link between child sexual abuse and eating disorders has implications for the treatment and prevention of eating disorders. Ultimately, eating disorder treatment depends on changing the social conditions that underlie their etiology, and not simply on individual healing. This is because, as this chapter has argued, we need to consider ways of relating to human distress that go beyond *illness* and *pathology*. Indeed, the prevention of eating disorders depends on women's access to cultural, political, social, and sexual justice. Secondly, we must reconsider how we approach the topics of child sexual abuse and eating disorders. This is not a matter of selecting or fine-tuning one approach over another. Rather, it is about rethinking how our approaches and methods frame the basis through which we understand trauma, silence, violation, emotions, and the body in the context of child sexual abuse and eating disorders. It is about rethinking how our approaches frame human beings' capacity and agency to respond to, and make sense of, and resist trauma while living a livable life. My hope is that this chapter has made readers more aware of the rich promise of utilizing dialogic theory. Although none of us can be freed from ideological biases, I hope we can be freed from a kind of monologism that turns all ideologies into falsehoods. I also hope that the capacity of creative arts to convey meaning in alternative ways is realized, and that drawing and poetry will be incorporated into more research methodologies, especially when exploring facets of human experience too difficult to describe in words, yet too important to ignore.

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Feminist Dilemmas in Researching Women's Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise

119

Lizzie Seal

Contents

1	Introduction	2080
2	Researching Women's Violence	2080
3	Questions of Researcher Allegiance	2083
4	Questions of Representation	2085
5	Questions of Ambivalence and Compromise	2087
6	Conclusion and Future Directions	2089
	References	2090

Abstract

This chapter explores feminist dilemmas in researching women's violence. It suggests that women's use of violence is a sensitive topic for feminist researchers because feminists have sought to delineate the role of male violence in continuing women's subordination. Highlighting women's violence potentially detracts from this. Feminists also wish to avoid lending credence to misogynistic and anti-feminist stereotypes, which inaccurately claim that women are equally as violent as men. Researching women's violence using feminist methodologies, which place value on creating knowledge from women's experiences, hearing marginalized voices, and democratizing the research process, raises dilemmas. The chapter considers these dilemmas across three areas – questions of allegiance, questions of representation, and questions of ambivalence and compromise. Allegiance refers whether researchers are “on the side” of their research participants, which can be a complex issue if their research participants have harmed others. The politics of representation are significant to how data are interpreted and how research participants and their actions are portrayed when writing up

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sensitive data. Researchers may experience feelings of ambivalence when they find their research participants difficult to empathize with and this can compromise researchers by making them in some sense vulnerable. The chapter discusses a range of examples in order to highlight these issues. Due to the limited methodological literature specifically on women's violence, it also draws on insights from other relevant feminist and criminological studies.

Keywords

Women's violence · Feminist methodology · Allegiance · Politics of representation · Ambivalence

1 Introduction

Researching violence by women from a feminist perspective poses some substantial dilemmas. For feminists, this is a sensitive topic entailing thorny ethical and political issues. The concept of "sensitive research" is well-established and refers to research which has the potential to cause harm (particularly emotional harm) to the participants and researcher (Dickson-Swift et al. 2007; Liamputtong 2007). Violence is a sensitive topic as it involves behavior that is manifestly harmful to others, and which also lays the perpetrator open to state-sanctioned punishment (Lee and Renzetti 1993). More than this, researching violence "raise[s] wider issues related to the ethics, politics and legal aspects of research" (Stanko and Lee 2003, p. 3).

This chapter examines methodological issues for feminist researchers engaged in researching violent women. In particular, it addresses questions of allegiance – whether researchers are "on the side" of their research participants, the politics of representation entailed in writing up sensitive data, the feelings of ambivalence researchers experience when they find their research participants difficult to empathize with and the ways in which this may compromise them. Before considering these issues, the chapter explicates why women's violence is a sensitive topic for feminist researchers and reviews feminist studies in this area.

2 Researching Women's Violence

Feminist methodologies have been employed to build a significant and indispensable body of research on gender violence. These methodologies emphasize democratizing the research process, enabling marginalized voices to be heard, taking a reflexive approach, and creating knowledge that will lead to political change (Hesse-Biber 2012). Feminist research is not distinguished by use of a particular method or approach, but rather by its grounding in feminist theory and ethics (Ramazanoglu and Holland 2002). Violence against women has been a crucial strand of feminist research and "is one of the most sensitive areas of research that feminists are engaged in" (Skinner et al. 2005, p. 10). In order to challenge women's subordinate

position in patriarchal societies, it is necessary to both fully understand and combat violence against women.

Violence *by* women is less well researched by feminists and it is necessary to ask whether it is a suitable topic for feminist research at all. As Burman et al. (2003, p. 74) assert, “feminists have traditionally ignored female violence, fearing potentially negative political and social costs for the feminist movement more generally.” This avoidance is explicable in the context of women’s comparatively low use of violence, particularly in its serious and lethal forms (DeKeseredy 2011; Hester 2013). Ristock (2002, p. x) identifies that “[s]ecrets are sometimes kept for strategic reasons within liberatory movements such as feminism that are trying to eradicate the globally pervasive phenomenon of male violence against women.”

There is a danger that attention to violent women confirms or lends credence to misogynistic fears and misperceptions, which lead to exaggerations about the prevalence of violence of by women (DeKeseredy 2011). Women who use violence are frequently demonized in ways which replay wider, sexist stereotypes (Seal 2010). Renzetti (1999, p. 51) admits that she was initially reluctant to research women’s use of violence “for fear that my work will be used against women.” She identifies the belief that “women are as violent as men but are not held accountable for their violence” as a supporting principle of antifeminism (p. 42). However, as she persuasively argues, far from this being a reason that feminists should avoid researching violent women, it is essential that they do so from a feminist perspective and via use of feminist methodologies.

Where violence by women, even fatal violence, can be contextualized as a response to violent abuse from male partners, it more easily fits into feminist frameworks (Seal 2010). However, there are also many feminist studies of more “atypical” violence by women, which is not in response to male violence. Child abuse and sex offending by women have been analyzed from a feminist perspective (Fitzroy 2001; Matravers 2008), as has women’s interpersonal violence in same-sex relationships (Ristock 2002; Hester and Donovan 2009). There are feminist studies on women who kill their own children (Wilczynski 1997; Oberman and Meyer 2008). Seal (2010) examines cases of women who commit “unusual” murders – that is, where they have killed someone other than a male partner or their own child. This encompasses a wide array of these rare cases, from the murder of a female relative to “serial killings.”

Bringing feminist perspectives to studying women’s violence enables it to be contextualized, particularly as women who commit violence are portrayed in the media and elsewhere as transgressive, having violated norms of nurturance and care. They may be described as unnatural or even as “monsters” (Morrissey 2003). Feminist research can challenge sexist and antifeminist stereotypes about violent women by situating their actions in relation to socioeconomic factors, past experiences of abuse, and social isolation. Oberman and Meyer’s (2008) interviews with women imprisoned for killing their children reveal common themes of poverty, abusive relationships (with partners and with parents), and gaps in social welfare provision. Matravers (2008, p. 305) explores how the preconviction lives of female sex offenders in her research “were characterised by social isolation and

disadvantage.” Many had histories of substance abuse and depression. By raising the significance of gendered social inequalities to women’s violence, feminist research helps to contextualize it in relation to the realities of women’s everyday lives (Burman et al. 2001).

Kruttschnitt and Carbone-Lopez’s (2006, p. 345) analysis of women’s narratives of their violence highlights reasons for violent behavior that range beyond prior victimization and social deprivation to include “the desire for money, respect and reparation.” Giving prominence to women’s narratives of their own violent behavior fulfils the feminist principle of taking women’s experiences as the basis for research (Ramazanoglu and Holland 2002) and characterizes several feminist studies of women’s interpersonal violence (Kruttschnitt and Carbone-Lopez 2006) and of women who kill (Oberman and Meyer 2008). These studies also seek to highlight women’s agency in using violence, without resorting to stereotypical or anti-feminist explanations (see also Morrissey 2003).

Another important aspect of feminist research into women’s violence is to assess their treatment by the criminal justice system. Studies demonstrate that policies which encourage or instruct the police to make arrests in reported incidents of domestic violence have led to the disproportionate arresting of women, despite their lower likelihood, in comparison with men, of using physical violence, threats, or harassment (Hester 2013). Ballinger’s (2000) study of the 15 women executed in twentieth-century England revealed that although overall women were more likely to be reprieved from the death penalty than men, where they had killed adults rather than children they were actually statistically less likely to be reprieved. Ballinger (2011, p. 112) emphasizes the need for feminists to create alternative knowledge to that generated by state-mandated punishment in order to “reconstruct new configurations of ‘truth’ which allows hitherto silenced groups to speak for themselves.”

Feminist perspectives must be applied to women whose “deeds fall between the cracks of the normative representation women” (Frigon 2006, p. 4) in order to advance feminist aims of “challenging stereotypes and restrictive gender norms” (Seal 2010, p. 3). Attention to the gender representation of violent women helps to illuminate how the norms of “appropriate femininity” are socially and culturally maintained. In her study of 28 Canadian women found guilty of murdering their husbands, 1866–1954, Frigon (2006) argues that judgments of women’s performance of their wife and mother roles were particularly significant. Such judgments can have implications for women’s sentencing in the criminal justice system (Wilczynski 1997), but also serve “the interests of both state and patriarchal power by reproducing discourses that circumscribe women’s roles” (Seal 2010, p. 7). Women’s violence threatens the gender order, and social, legal, and cultural responses to it reflect “more general, inchoate anxieties about the potential for the feminine character to disrupt the order of things” (Heberle 2001, p. 55).

There is a strong case to be made for feminist research on women’s violence and there is an increasingly well-developed existing literature on this. However, this does not diminish the fact that substantial dilemmas attach to researching violent women using feminist methodologies. These relate not to the selection of methods, but to the ethical and political issues that the research entails. Feminist methodologies are

rooted in a political commitment to ending women's subordination, but also to bringing feminist principles to the research process. As discussed above, these include undertaking research from a position of solidarity, eroding power differences as far as possible, and enabling marginalized voices to be heard and with the aim of effecting positive change.

Some of these principles are complicated, or even potentially attenuated, when researching women who have harmed others. While there is feminist work to be done in terms of contextualizing women's violence and challenging derogatory and limiting stereotypes, the researcher is also faced with the reality that the women they research have caused the suffering of others. This may limit the empathy that researchers can feel with them and can induce feelings of ambivalence (Seal 2012). The rest of the chapter discusses these ethical and political issues for feminist research on women's violence. As there is only a very small methodological literature on research in this area, it draws on relevant wider literature from criminological and feminist research in order to do so.

3 Questions of Researcher Allegiance

In order to unpack issues of allegiance as they relate to criminological research, Liebling (2001) returns to Becker's (1967) famous question to sociological researchers – “whose side are we on?”. She asserts “any social research is also a human process and it can therefore be fraught with personal dilemmas” (p. 481). Research is also necessarily political “because it involves wielding power” (p. 481). Liebling (2001) reflects that criminologists who firmly place their allegiance with the imprisoned or those classed as “offenders,” and oppose attempts to see the perspective of the “superordinate” such as prison governors and police officers, have moral courage and a strong sense of what is right – but this inflexibility can seem troubling. The complexities of the social world and the tensions between different values are not addressed if the researcher firmly pledges allegiance before conducting the research. Liebling (2001) argues that to acknowledge this does not remove the validity of a political position, or the desire to advance social justice through research. Rather, researchers need to recognize the contingency of their values.

For feminist researchers, the answer to “whose side are we on?” would be those who are disadvantaged by gender power imbalances. This frequently means women, but also includes men. Due to their social positioning, women who use violence do usually fall within this category – as discussed above, they are vilified as evil, masculinized, or dismissed as not in control of their actions. However, in many circumstances, they have also misused their power against others – especially in “atypical” cases. To straightforwardly declare to be “on their side” would erase the suffering of their victims. The choice of allegiance is uncertain and can be troubling (Liebling and Stanko 2001).

Much of the time, social science researchers do not put themselves in the position of researching people with whom they cannot form an empathetic relationship

(Godfrey 2003). Allegiance can be relatively straightforward in studies of people who are socially marginalized or excluded, but less so when they are “morally marginal” and without “victim-status,” and where “more ambiguous moral and empathetical positions” are involved (p. 57). Criminological research involves venturing into this ambiguous territory when it focuses on convicted murderers, pedophiles, and other serious sex offenders. The challenge for researchers becomes one of how to deal with exploring morally unacceptable behavior “whilst still attempting to understand the context of their subjects’ lives” (Godfrey 2003, p. 58).

Sollund (2008) faced this challenge in her interviews with minority ethnic men in Norway who had been convicted of crimes against women. She focused on two interviews with men who had killed women, one of whom who also raped his victim. Sollund argues that researchers often omit their feelings from their published accounts of their research, whereas she came to understand her feelings toward these interviewees as significant to the data she collected. One of the men, John, had stabbed a woman to death while he was severely mentally ill. The crime had been reported widely in the media, and Sollund was shocked, when she interviewed him, to realize that he was the perpetrator of this crime. However, she felt sympathy for John and believed “he was a genuinely good person” (p. 188) as he was quiet and respectful, and expressed remorse. Yusuf, on the other hand, “had an offensive attitude in the interview” and came up with excuses for his actions (p. 188). Sollund felt that he was dangerous and hoped that he would not be released from prison. Both men had come to Norway as refugees and Sollund reflects that she could be “accused of taking advantage of the vulnerable situation of male refugees with an uncertain future” (p. 184). She also acknowledges that she found it easier to appreciate the wider context and mitigating factors of John’s situation because of his demonstration of shame and remorse than Yusuf’s, even though she knew that Yusuf had been a forced soldier before fleeing to Norway.

Cowburn’s life history research with incarcerated male sex offenders (Cowburn 2007) was undertaken from a profeminist standpoint as his aim was to help change dominant and harmful forms of male behavior. Taking a reflexive approach, Cowburn (2007, p. 284) analyzes his own role in the interviews and relates how he found it “impossible to listen passively to justifications of abuse.” He provides the example of one particular interview in which the participant described the sexual abuse of his daughter as resulting from “excessive love” (p. 285). Cowburn directed the conversation in a way which enabled him to challenge this man’s beliefs, but acknowledges that he was able to do so because of the power and authority he had as the interviewer. Asserting researcher power over the participant in an interview situation breaks the principle of feminist methodology of democratizing the research encounter. However, not to have challenged the man’s justifications could have seemed like an endorsement of them. Cowburn (2007, p. 286) concludes that “allegiances are not always simple.”

Similar issues were faced by Blagdon and Pemberton (2010), who also interviewed convicted male sex offenders. Such men have of course mistreated and caused the suffering of others, but their marginalized and stigmatized position within both prison and the wider community means that they are also vulnerable,

which needs to be recognized by researchers. Building rapport with participants was important but meant that Blagdon and Pemberton (2010, p. 272) “had to reconcile their own moral positions” with this. This could, on the one hand, be because they found that they liked a particular interviewee, or on the other could be because they disliked them. Like Cowburn (2007), they also faced the dilemma of how not to seem like they were colluding with interviewees’ justifications of abusive behavior without directly challenging them. In answer to whether researchers must take sides, Blagdon and Pemberton (2010, p. 278) argue that they must “see the merit in both sides” – in their case, their participants’ perspective and also that of the prison regime, which was specifically designed for sex offenders – while appreciating the tensions that this produces.

In my archival research from case files on women accused of murder in mid-twentieth-century England and Wales (Seal 2012, p. 695), I encountered cases where the woman was not easy to sympathize with “as the circumstances of the killing did not exemplify feminist concerns about gendered power differences” and questions of allegiance were vexed. One of these was a 54-year-old woman named Renee Hargreaves, who poisoned Ernest Massey, a 78-year-old family friend who had come to live with Renee after his wife died, by putting weed killer in his tea. She was found guilty of involuntary manslaughter on the basis that she had only intended to make him ill, rather than to kill him, and she received an 18-month prison sentence. Circumstantially, it appeared from the case file material that Renee may have intended to kill Ernest as the pathologist believed that he had been poisoned over a period of 2 or 3 days. She also stood to inherit money from Ernest.

In this work, I note that “Renee’s case poses the dilemma of carrying out feminist research without strong feelings of empathy” for the woman in question (p. 695). Renee killed someone with relatively less social power than she had and she was not treated harshly by the criminal justice system. I acknowledge that in my study I could not “place [my]self ‘on the side’ of the women accused of murder as many of them had done terrible things, and to people who were less powerful” than they were (p. 695). This raises the question of “what to do with emotional reactions” that do not contribute to feminist politics (p. 695).

4 Questions of Representation

Blackman (Blackman 2007) addresses the issue of “hidden ethnography,” which is where the researcher’s emotional reactions to their participants are absent from completed, published accounts of the research. This could be because this data is controversial or because revealing such emotions poses a threat to the researcher or their participants. The necessity of not only recognizing that research is an emotional process, but also of incorporating reflection on researchers’ emotional responses into data analysis, is increasingly accepted (Holland 2007; Liamputtong 2007; Dickson-Swift et al. 2008; see also ► Chap. 123, “Emotion and Sensitive Research”). However, this becomes complicated when negative emotions are entailed that do not seem to contribute to the aims of the research.

Such dilemmas arise from the complexity of the politics of representation. Kirsch (1999) examines how the politics of interpretation and representation are significant to feminist research. Feminists may face “interpretive conflicts” when interviewing women who do not share their values. There is no easy solution to how to represent this in published accounts and how to avoid the unequal power dynamics at play between the researcher and the researched. Writing up is where the researcher exercises the most power over their research participants as they present the definitive version of their findings and of the research process itself.

The dilemmas of carrying out feminist research with “unsympathetic” women are explored by Luff (1999) in relation to interviews she conducted with women in the “moral lobby,” which has generally been characterized as “antifeminist.” As a woman from a white, middle-class background that was similar to that of her participants, Luff could establish rapport with them and could also experience feelings of warmth toward some of the women. In general, however, they expressed views that contrasted sharply with her own. Adhering to the principles of feminist research, such as equalizing power relations, was by no means straightforward. The interviewees were relatively socially powerful women, but as research participants Luff (1999) exercised a degree of power over them in terms how she represented them in published accounts. Luff (1999, p. 699) felt an ethical commitment not to include in her writing the views participants expressed on feminism where such material could potentially compromise confidentiality and “might place them in a potentially vulnerable or marginalised position within their organisations.” This was a dilemma as it meant collusion, on the part of a feminist researcher, with the women remaining in antifeminist organizations.

One frequent way of challenging othering and marginalization is to offer more positive imagery that counters derogatory stereotypes. However, it must be acknowledged that representations of disadvantaged and subordinate populations cannot always be positive (Hall 1996). Hester and Donovan (2009) reflect on feminist discomfort in relation to researching domestic violence in same-sex relationships. They state that “there were strong tendencies to minimize, hide, and deny the existence of such abuse” due to the fear of exacerbating homophobia or seeming to offer support to conservative discourses of “traditional family values” (p. 162). These questions of how to represent “troublesome” data and research participants are questions of ethics and morality, and do not have straightforward answers (Preissle and Han 2012).

The notion of “hidden” data applies to documentary methods, as well as to fieldwork. In some ways, it has even greater relevance as documentary research frequently entails sifting through hundreds of pages of data, only a tiny fraction of which can be quoted in published research. Unlike interview transcripts or ethnographic fieldnotes, the chance to consult subjects on their feelings about what should be included is usually not available. In my research on women accused of murder (Seal 2012), I found indications of prior violence toward their victims on the part of the some of the women. One of these was Marilyn Bain, a woman in her twenties who in 1962 stabbed her female flatmate, Jan, in the ribs. Jan died 3 days later after her wound became infected. Marilyn’s statement to the police referred to “quarrels”

between her and Jan and also explained that when fighting, she always punched Jan in the ribs rather than the face so that she would leave no clearly visible marks. To me, this account seemed to bear strong similarities with the actions of male perpetrators of violence against women, raising the danger of confirming antifeminist arguments about the prevalence and nature of women's use of violence (see also Renzetti 1999).

In terms of the politics of representation, data such as this demands the feminist researcher's recognition of women's interpersonal violence toward other women, and its parallels with men's violence against women. This does not mean succumbing to antifeminist arguments that overstate women's violence and underplay men's, but it does entail the "dangers of knowledge" (Ristock 2002). My other published work on Marilyn Bain's case does not include discussion of Marilyn's violence toward Jan before the night of the stabbing (Seal 2009a, 2010). This is because my research questions concerned gender representation in the criminal justice system and Marilyn's account of punching Jan did not feature in portrayals of her femininity. However, reading file material such as this created ambivalence in terms of how I felt about the women I researched and complicated the issue of allegiance (Seal 2012).

A different publication from my research (Seal 2009b) examines the public sympathy that was expressed for Edith Chubb, a woman who in 1958 killed her sister-in-law, Lilian, by strangulation. She was convicted of involuntary manslaughter and sentenced to 4 years in prison. Although violent women have frequently been vilified in both historical and contemporary contexts, I explore how Edith's portrayal as a respectable, hard-working woman and "put upon" mother facilitated positive responses to her case in the form of a newspaper-led campaign to release her from prison. This campaign involved establishing a dichotomy between Edith as an overworked mother and Lilian as a "lazy" spinster (Lilian was in full-time paid work). In terms of the politics of representation, I highlight how derogatory stereotypes of unmarried womanhood constructed Lilian as a "deserving" victim. Cases where women receive public sympathy can be used to reinscribe antifeminist arguments about undue leniency toward violent women. It is, therefore, necessary to pay close attention to the complexities of representations of femininity, particularly how certain "positive" portrayals may be constructed in relation to other negative stereotypes of womanhood.

5 Questions of Ambivalence and Compromise

Reflexivity, the "self-critical sympathetic introspection and the self-conscious *analytical* scrutiny of the self as researcher" (England 1994, p. 82, italics in original), is central to feminist approaches. This principle demands that the ambivalence entailed by researching violent women is admitted to and discussed. Ristock (2002, p. 39) conceptualizes reflexivity as the willingness to look at "my own meaning-making processes." She describes her research into interpersonal violence in lesbian relationships as exposing her to the "dangers of knowledge," especially as she had extensive

experience as an activist in relation to men's violence against women (p. 41). In their research on child abuse, Jackson et al. (2013, p. 9) noticed that "female-perpetrated abuse was experienced as particularly problematic to grasp." Employing "emotional reflexivity," they concluded that this particular difficulty in comprehending abuse by women resulted from the "gendered norms of care" held by some members of the research team (p. 9). Therefore, reflexivity is essential to unpacking the influence of the researcher's own anxieties, assumptions, and feelings in relation to violent women.

Mixed feelings about research participants are, to at least some degree, likely to be an element of most research, feminist or otherwise, that takes an in depth look at human beings. Tensions and contradictions are part of the research process and must be navigated. Researchers must live with "ambiguity, difficult decisions, and a certain openness to change in the world" (Plummer 2001, p. 228). Where topics are sensitive or controversial, feelings of ambiguity and ambivalence often come to the fore. These must be negotiated in order to achieve reflexivity (Hollway and Jefferson 2012). Ordinary life is characterized by "complexity, paradox, provisionality, changeability and unpredictability," which cannot be erased from the research process – and may also be necessary in order to achieve understanding of what is being researched (p. 165).

Campbell (2002, p. 28) recommends that researchers ask, "What do we feel conflicted about and why?" in order to gain insight into moments of discomfort. This issue is considered by Reeves (2010), who conducted ethnographic research in a probation hostel for sex offenders. Once she had left the hostel, she sometimes encountered former participants in the street. This made her uneasy as the men were classified as high-risk offenders, but also ashamed of this unease because the purpose of her research was to shed light on their little understood experiences of the criminal justice system. This "ethical and emotional conflict" was only resolved by the lessened of chance meetings as participants were removed from the area, and then by Reeves' own move away for unrelated reasons (Reeves 2010, p. 328). She reflects that her unease arose from the changed context that chance meetings entailed – the protection of the hostel institution was no longer there.

Friedman's (1991, p. 109) exploration of the emotional facets of qualitative fieldwork notes that researchers can become "too close" to their participants, but can also experience "negative emotions that threaten to interfere with the development of an in-depth understanding of the people whose lives are being studied." Friedman's research was with female police officers and after spending much time with them, she felt close to them. However, this entailed recognizing aspects of their behavior that she would prefer not to have seen. She saw that "some of the women police officers whom I had grown to like were overtly, unapologetically racist" (Friedman 1991, p. 115). Whether to include this material in written versions of the research was a dilemma in terms of the politics of representation as she had an "impulse to portray the women consistently in the most flattering light possible" (p. 116).

Presser (2005) makes the case for carrying out feminist research with violent men. Such research needs to help identify why men perpetrate violent crimes but also,

more controversially, needs to pay attention to “the humanity of the men” (p. 2067). She argues that feminist criminologists situate women’s offending in relation to social marginalization and inequality, but “are not ‘doing feminist methodology’ when it comes to studying violent men” (p. 2068). In order to remedy this, she asserts that feminist researchers should employ “strong reflexivity,” which incorporates the wider social, economic, and political contexts of men’s actions. In identifying violent men, researchers rely on the power of the state to provide access to incarcerated participants (or in keeping records that can be accessed by documentary researchers).

This power imbalance between the researched and researcher should be acknowledged, even where the researched in question are men who have committed violent crimes against women. Presser’s (2005) interviews involved being sexualized by some of the men, but she also felt empathy for them, particularly for one participant who was on death row. She articulates how ambivalence in research is not restricted to personal emotions but also to political positions. Her feminism meant that she wanted to challenge male violence but also to highlight the social positioning of marginalized men and the state’s control over them.

In an article which considers Presser’s (2005) account among others, Griffin (2012) develops the notion of the “compromised researcher.” She applies this in particular to feminist researchers and explores examples of where they have been made vulnerable or in some way contaminated by their research, whether through choice of topic or methodology. She does not use the term “compromised” to allege unethical or unsatisfactory research practice. Rather, Griffin argues that researchers are compromised because of certain assumptions and conventions that attach to feminist research. One assumption is that in feminist research “you are what you do” and that for it to be otherwise inevitably compromises the research (p. 337). This means that there is a convention for feminists to research “the same” – in other words, other women – and to choose topics that are “close to their heart” and of which they have personal experience (p. 339). Remaining within these conventions entails its own compromises and vulnerabilities for the researcher, but stepping outside of them to research the “different” and “not experienced” raises questions about the researcher’s ability to fully and ethically represent their subjects.

6 Conclusion and Future Directions

Unlike researchers such as Presser who have researched violent men, researchers who are both female and feminist who study violent women are researching “the same” in terms of shared gender (although their subjects may well be different in terms of social class position, ethnicity, sexuality, and age). As discussed, this potentially entails compromise in terms of the politics of representation by highlighting behavior that feeds into misogynistic and antifeminist portrayals of women. Despite being women researching other women, developing empathy and allegiance with violent women may be difficult or even undesirable for feminist researchers. Feminist research on violent women may seek to deconstruct derogatory stereotypes,

to place women's violence "within wider contexts of social inequality and marginalisation" (Seal 2012, p. 698) or to highlight previously overlooked forms of victimization. However, it would not be ethical to uncritically pledge allegiance with violent women as research participants on the basis that they may have been negatively portrayed and/or "ended up as state defined 'offenders'" (Seal 2012, p. 698).

The complexity and ambivalence of these cases must be analyzed and lived with via a reflexive approach, with all the compromise that this may engender. Although there is a thriving feminist literature on different aspects of women's violence, there remains a paucity of methodological discussion within this. Future research in this area should provide further consideration of reflexivity, emotions, allegiance, and ambivalence as they relate to feminist studies of women's violence.

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Animating Like Crazy: Researching in the Animated Visual Arts and Mental Welfare Fields 120

Andi Spark

Contents

1	Introduction	2094
2	Background to the Project	2094
3	Methodological Approach: In Detail	2098
3.1	Identifying a Triangulated Heuristic Framework	2098
3.2	Identifying Symptoms of the Health Condition	2099
4	The Creative Structural Process	2100
4.1	Snapshots and Thumbnails	2100
4.2	Fragments and Vignettes	2101
4.3	Incorporating Humor	2103
5	Affordances of Animation	2104
5.1	Visualizing the Invisible	2105
5.2	Penetration	2106
6	Conclusion and Future Directions	2107
	References	2108

Abstract

This research straddles the divide between creative arts practice and social science methodologies, with a focus on outlining a practical approach to developing short-form mixed-media format animated projects that address serious issues such as postnatal depression. Using a multimethod approach that incorporates elements of heuristic, practice-based, autoethnographic, and narrative enquiry methodologies, this chapter describes how animation can be utilized for both communicative, informative, and entertaining purposes. Explaining how animation works in emphasizing symbols and metaphors to elicit empathetic responses, and using examples from various independent creative practitioner's approach to

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their work, the focus here is on delivering authentic and authoritative projects for a targeted audience.

Keywords

Animation · Mental health · Postnatal depression · Mothering · Creative arts practice · Fragmented narrative communication

1 Introduction

The practical aspects of researching within the visual arts are readily covered through a practice-based or practice-led methodology (Hamilton and Jaaniste 2009; Biggs and Henrik 2010). This approach is also common in animation production research, whereby the practitioner develops screen-based artworks through a process of writing, image making, and compiling a creative output in a critical feedback loop cycle (Brown and Sorensen 2008; Barrett and Barbara 2010). Researchers in the health and social science area nominally follow a structured gathered-data based approach, being one example among many other common methodologies (Denscombe 2010). This chapter looks at a multimethod approach as a convergence of enquiry into ways animation can effectively be used to convey social health and welfare issues in a nondidactic format.

My research explores the context and practice of creating an animated project specifically responding to the issue of postnatal depression (PND). The study takes an exploratory self-reflective practice approach wherein I examine my own and others' experiences and responses to mental health issues surrounding childbirth. I correlate these to associated themes of the representation of adult women, social constructs and expectations of women as mothers, concepts of taboo and abjection, along with ideas of embodiment, memory, and fragmented storytelling. Coupled with this, I employ an analytical data-based review of scientific and medical knowledge of the postnatal depression field and connect these aspects of information (creative, sociological, and medical) into script development for animation. Further iterative development occurs in a heuristic mode, taking into account my own knowledge-based and intuitive practice (including use of technology, storytelling methods, and use of visual symbols and metaphors) to create new ways of expressively conveying information. The project is realized as a transmedia style interactive web-based series of animated vignettes, entitled *Coming Through*.

2 Background to the Project

Some background to this project is essential in understanding the methodological approach. I developed the *Coming Through* project by directly responding to my own experiences as well as anecdotal evidence of others' experiences and through reviewing the list of recognized PND symptoms that have been identified through

clinical practice evidence. The methodology comprised a distinctive heuristic approach (Moustakas 1990), documenting human experience through including auto-ethnographic (Orbe and Boylorn 2014; see also ► Chap. 30, “Autoethnography”) and grounded theory research (Buchanan and Bryman 2011; see also ► Chap. 18, “Grounded Theory Methodology: Principles and Practices”) along with information analysis combined with action-based practice (Pink 2012). It also considered elements of documentary and pondered notions of authenticity and truth within the fictionalized genre of animation. A focus on gathering information and data on specific mental states via clinical practice evidence affords an element of authenticity and epistemological truth, unclouded by sentiment or cultural bias. However, my intention for this project is to highlight the deeply personal lived experience of people encountering this illness. This methodology is common to expressive documentary treatments, used in both collateral therapy (Carlisle et al. 2009) and narrative/informational contexts. A striking example of animators working with mental health patients in therapeutic and creative ways are Swiss filmmakers Nag and Gisele Ansoerge’s 20-year project (1962–81), where they gathered stories and testimony from psychiatric patients at the Cery Hospital Psychiatric Clinic of the University of Lausanne, Switzerland, from which they created film vignettes (for example, “The Poet and the Unicorn” [1963], “Seven Nights of Siberia” [1967]). As a filmmaker, Ansoerge was deeply affected by the exposure to the patients, which also translated into highly engaging audience encounters. He states:

The way in which the patients analyzed things and made judgments allowed me to learn to know myself better. I discovered a world profoundly human, which had to work with very great suffering, the intensity of which is hard to imagine. . . . These films should not arouse compassion, but rather an interest and a sense of active conscience in the face of the mystery of mental illness. (Ansoerge 1998, p. 38)

In this same way, I draw attention to a general audience’s consciousness about PND and reexamine my own notions of maternal mental health and well-being in the framework of identifying as an animatrix (essentially, an animation practitioner with a woman-centered focus).

The “story” of PND is complex and multifarious; each affected woman experiences different symptoms in different ways (Buist et al. 2009). Thus, I endeavored to accommodate this complexity in my approach to developing the project. My aim is for the work to remain multifaceted, affording a space for a variety of voices. Therefore, the project is designed as a series of animated vignettes, each responding to one or more of the identified symptoms, such as feeling inadequate or worthless as a mother, being exhausted, empty, sad, tearful, or being unable to think clearly or make decisions. Some of these overlap or involve nuances and subtleties; for example, “empty, sad, and tearful” may evoke images of crying, but this symptom also correlates to “not being able to cry.” The differences between being “sad” and “empty” can also be interpreted in varying ways. The vignettes or episodes are intended to work as a memory jog, providing a moment of recognition in either the visual or thematic content. Although aimed at an ideal audience of postnatal mothers, it is not intended to provide a therapeutic function, moreover offering an

engaging entertainment. However, with further development and engagement with health professionals and organizations, this may become possible. Humor is another essential factor in this project. Rather than a verbal gag or pun, the kind of humor here operates on the shock of an unexpected visual twist or an ironic juxtaposition of elements. Many of the vignettes are inconclusive; they do not rely on a punchline, climax, or denouement. Some aspects of the humor rely on popular culture references, such as a “used-car salesman” characterization. However, these are in almost universal contemporary use so as to be recognizable across most modern cultures and age groups. Rather than focus on a political or overtly didactic approach, I am more concerned with the idea of communal connection in a similar way to Vera Neubauer’s films (Neubauer [n.d.](#)). In an interview and profile piece about her animated career, Leslie Felperin ([2012](#), p. 71) states:

In contrast to the worthy agit-prop of some feminist animators, Neubauer’s films refuse to preach and seem to prefer to problematise through abstraction and personalise through the use of autobiography that declines to claim for itself any universal application, while still inviting the viewer’s identification.

The project is constructed to also contribute to an entertaining, information-based website where the vignettes can be accessed individually or reviewed as a whole series. The vignettes are accessible in random order, in much the same way that experiencing the illness does not necessarily occur in any particular order. Also, more importantly, not all symptoms present in all people, so the site is intended to be searchable to enable viewers to find an episode that particularly relates to them. It is also possible to view an assembled edit of a number of vignettes to be watched in the form of a short film.

In the first iteration of what is expected to be a long-term and larger-scale project, the works were collated and screened in looping sequences on very small screens (iPad minis) displayed concurrently. One defining aspect of creating transmedia works, in that they can be effectively displayed across a variety of distribution modes, for example, from small-screen mobile devices to gallery-based projections. The design of the project allowing for interactive selection encourages further stories to be potentially collated from viewers and readers who may contribute another anecdote of an event or situation that is a variant descriptor of a particular symptom. These can be translated into illustrations or animations. In the long term, for example, there may be five or six (or more) different ways of showing the concept of “appetite change” or “extreme lethargy” which can be added to the site creating that polymorphous “voice” noted previously.

It is imperative that each episode is short, as women suffering through this condition have very little available time, and most of it is in short bursts. They also have a considerably lower cognitive load due to the demands of multitasking in caring for a baby. Using simple sketch-like images adds to the sense of immediacy and of a story being told by “everywoman” and stories shared between friends and told in the “now.” Again, this channels Neubauer’s approach of using a strong graphic style “which gives a sense of swift and urgent execution, does not fetishise

technical perfection” (Felperin 2012, p. 70). Essential to this stylistic treatment is the consideration that these microstories or vignettes are a small part of a larger, more comprehensive, voice that will encompass multiple viewpoints from various women, even from individuals with multiple ways of recounting their experiences. As Felperin (2012, p. 70) continues,

...Neubauer’s films attempt to tell stories through montages of striking images and fragmentary scenes which refuse to pull the wool of linearity over the spectator’s eyes. Instead, the time of her narratives is fractured, the ‘plots’ cut up and reassembled on the editing table, evoking the feeling of stories half-remembered, narrated by someone perhaps with... digressive tendencies...., or perhaps with unreliable memory, or perhaps just someone trying to say not ‘this and then this’ but everything at once.

The sketch drawings in *Coming Through* are easy to read, being uncluttered and with an almost naïf/naïve quality that does not require sophisticated renderings of perspective or depth of field. In his book *Understanding Comics*, artist and theorist Scott McCloud (1994, p. 30) argues that the abstracted cartoon image emphasizes specific details and that by “stripping down an image to its essential ‘meaning’, an artist can amplify that meaning in a way that realistic art can’t.” Similarly, the character design and visual vernacular mimics a simplified cartoon style. Honess Roe (2013, p. 110) emphasizes the way that we perceive words and images differently and that our understanding of visual language predates our formal education in verbal and textual language, whereby images can reach the emotions before they are cognitively understood. This is a deliberate contrast to most other works in this genre (i.e., information or communication videos about maternal health issues) that use live-action testimonials. In this way, a cartoonified character can potentially appeal to a greater demographic, in that engaging the audience is not restricted to their personal identification with the actor or persona on screen (e.g., race, status, age), which prevents them from “making judgements based on appearance” (Honess Roe 2013, p. 114). Honess Roe argues that “non-indexical media may be the most vibrant and evocative way of remembering the past” and, as I also argue, can evoke an internal feeling of recognition. Through the ability of the animated character to transform or transmogrify, possibilities for self-identification are enhanced. In this project, I use a lead character based on a rough caricature that represents myself.

The embodied self as cartoon character becomes one step removed from the real me but also from the real viewer. Although the character may appear as a heteronormative nondysmorphic white female, she is intended to represent the pantheon of various bodies and selves. The caricature displays as a simplified female form, echoing McCloud’s construct of “stripping down... to essential meaning” in the same way we understand the Male/Female symbols denoting public toilets. In this way, metamorphosis is also an essential tool to quickly represent various body states, locations, positions, and mental images (Wells 1998, p. 69). Likewise, the use of signs and symbols is essential to rapid recognition in a short space of screen time. Many symbols can effectively take the place of dialogue or voice-over, which is an important consideration. The episodes are designed to be watched quickly and quietly (so as

not to disturb a sleeping baby) and intended to be available across cultures and language barriers. Visual communication tools including physical cues (postures and gestures), facial expressions (and eye movement), and the staging and spatial relationship between figures convey a more universal meaning than dialogue (Pease 1981). Despite this intention, there are also some episodes that incorporate text on screen as speech bubbles or thought bubbles as a short-cut to amplify the performance acting of the characters. In this way, instead of needing more screen time to fully act out the way the character may be thinking, the text can contribute to an explanation.

3 Methodological Approach: In Detail

The multimethods approach is necessary in this type of research to enable both the creative impetus to effectively couple with the scientific evidence. An initial heuristic approach applies to the creative development phase.

3.1 Identifying a Triangulated Heuristic Framework

According to Moustakas (1990), an early key theorist of heuristic research, there are six stages of heuristic research. The first stage, initial engagement, involves the researcher identifying an issue they are passionate about with personal and social implications. From there, a question will be formed. The second stage, immersion, implies that the researcher is immersed and deeply involved in all things related to their question. At the third stage, the incubation phase, the researcher takes a step back from the intensity of the immersion stage and allows their acquired tacit knowledge and intuition to clarify their understanding. The fourth stage, illumination, involves a breakthrough in understanding and awareness. The fifth stage, the explication phase, requires the researcher to examine their newfound understanding and to identify new constituents and themes arising from the illumination process. Creative synthesis is the final phase. This involves the expression of the themes and findings into a creative form.

In my specific multimethod approach, there is a distinctive break between the third and fourth phase, that extends to data examination and analytical review of the specific subject matter, from a scientific, medical, structural, and formal content basis. In this case, gathering information on the established symptoms and clinical presentations of postnatal depression patients from a wide variety of data sources. This is then synthesized to clarify the key analogous factors across different clinical data reports and a table or list is developed which then identifies and correlates the functional knowledge with the initial creative emotional response to the recollected symptoms or incidents. Further data gathering takes place at this stage, in collecting additional anecdotal responses from other sources, in this case including both verbal and written personally related stories. These are also tracked to the recognized symptoms. From here, the “script” will be developed, incorporating the initial immersive impressions, established factual data, and extended experiential reports. Essentially, this leads to the fifth phase describes by Moustakas, integrating new

constituent knowledge. However, this interim additional stage creates the relationship between a purely personal illuminative and expressive process and one that confers a clinical connection with medical and social science factual data.

3.2 Identifying Symptoms of the Health Condition

Briefly noting the facts associated with diagnosing PND (AIPC 2015) will help to understand the way the creative elements are incorporated into the project. Clinical and psychological research into this condition over the past 20 years, particularly that led by the late Professor Sherryl Pope and a team of researchers from the Women and Infants Research Foundation at the King Edward Memorial Hospital in Western Australia, has clarified a list of identifiable symptoms (Pope et al. 2000). These are categorized into three nonhierarchical areas: feelings, actions, and thoughts. They are listed below.

Feelings:

- having a very low mood
- feeling inadequate and a failure as a mother
- having a sense of hopelessness about the future
- feeling exhausted, empty, sad, tearful
- feeling guilty, ashamed or worthless
- experiencing anxiety or panic
- experiencing fear for and of the baby
- experiencing fear of being alone or going out

Actions:

- a lack of interest or pleasure in usual activities (including sex)
- insomnia or excessive sleep, nightmares
- appetite changes (not eating or overeating)
- decreased energy and motivation
- withdrawal from social contact
- not looking after personal hygiene
- inability to cope with daily routines

Thoughts:

- being unable to think clearly or make decisions
- experiencing a lack of concentration and/or poor memory
- thinking ideas about suicide
- thinking about running away from everything
- worrying about partner leaving
- worrying about harm or death occurring to partner or baby (Pope et al. 2000)

Diagnosed PND can occur within weeks or sometimes months after giving birth (Beyondblue n.d.; Black Dog Institute n.d.). It may not affect a woman until she weans her baby or until her second or third child is born. As LeBlanc (1999, p. 162) observes:

Postnatal depression does not normally strike suddenly on any particular day but takes hold insidiously in such a way that its presence may never be recognised or acknowledged by the mother, her spouse, the clinic sister or even her medical practitioner. Instead, her sense of wellbeing is steadily eaten away day by day until it seems to the mother, and everyone around her, that this is her 'normal self'. The longer the depression goes undiagnosed, the harder it becomes for a woman to admit that all is not well in her world.

PND can last from several weeks to months or even years, with up to 50% of women either diagnosed late or still reporting symptoms after 12 months (PANDA [n.d.](#)). Furthermore, "recovery has the sense of being two steps forward, one step backwards" (LeBlanc 1999, p. 162). The prevalence of PND is cited at around one in seven women, or approximately 15% of births (Cox et al. 1987). It occurs across social, cultural, and economic boundaries, and symptoms are universally comparable. However, it has been established that lower socio-economic status combined with limited maternal support are contributing factors to higher percentages (Buist and Bilszta 2006; Westall and Liamputtong 2011).

4 The Creative Structural Process

My working process straddles the two worlds of clinical-based communicative structures and an independently based intuitive model. The communicative structural approach focuses on preproduction and planning wherein every element of what will finally be seen on screen is meticulously preformulated. However, this research approach requires an allowance for spontaneous changes and unintentional additions or "happy accidents" in the execution, particularly because of the intimacy of the ideas and story. I commenced articulating my ideas with single image sketches as a kind of cartoon or comic picture, much like a snapshot at the core of the emotional and physical sense recalled from a period of depression. These initial sketches form keystone conceptual design images for the project and stimulated the animation process. Julie Roy (2012, p. 38), from the National Film Board of Canada (NFB), notes a similar *modus operandi* in Michele Cournoyer's filmmaking approach:

This importance accorded to the raw material of the unconscious is expressed in her process. She animates the initial fragment, then a second, a third, and so on. These fragments are then stuck on the wall in her studio. A storyboard gradually develops.

4.1 Snapshots and Thumbnails

In an interview in 2001 with the NFB, which provided support for the creation of her works, Cournoyer herself talks about the development of her work: "I never knew what was going to happen. I was communicating with my unconscious, the demons, angels and everything else inside me. I was in a state of need. It was utterly compulsive" (Roy 2012, p. 38). Following the initial concept sketches, "thumbnail

images” are created to plot out the action or scenario for each scene. In fact, many of the shots do not require a lot of “animating,” as the essence of the emotion can be read from a simple single image. At the time of creating this work, there is no sense of a linear narrative story, just fragments of memory and raw feelings. As Cournoyer reflects in her interview essay with animation critic, biographer, and director of the Ottawa Animation Festival, Chris Robinson, “It [i.e., the process] became more and more liberating, I worked in a primitive, direct communication with my devils and found the story in the execution” (Robinson 2005, p. 95). Pierre Hebert, a contemporary of Cournoyer and fellow Canadian, also reflects on the intensity of emotion Cournoyer expresses in her work: “I realised that she’s seeking a kind of welling up of material, where she gives expression to something that is beyond her control” (quoted in Roy 2012, p. 32). In the same way, channelling emotions is a way to revisit the raw intensity of an experience, that may translate to the screen more effectively than clinical or numerical data and textual facts.

My first raw early concept sketches include many “crying” images – overflowing tanks of water, volcanoes of tears, drowning – as well as graphical pop culture references, such as a snakes-and-ladders board representing losing the plot and the idea of taking one step forward and then fifteen steps back; a “Used Baby Yard,” replete with “snake-oil salesman” type character to trade in babies who cannot be adequately looked after by their mothers; and stereotypical supermarket sales banners and signs changing to threatening slogans of devouring babies (see Fig. 1 “Tears for No Reason,” Fig. 2 “Dodgy City,” and Fig. 3 “Desolator”). These sketches are then redeveloped into concept art works which serve as a signpost to the way the project could be envisioned, as well as the tone and treatment of the story, using visual and textual puns in the titles, such as “Tears for No Reason,” “Rain Hat,” “Dodgy City,” “The Desolator,” “Nutcase,” and “Taedium Vitae” (see Fig. 4 “Tired of Life”).

4.2 Fragments and Vignettes

Most animation productions, including short films, are predicated on a finished script. This is the format recognized by organizations that fund projects, although as noted, visual treatment, including character design and concept art, is also fundamental to understanding the range and scope of any project. However, in this case, the story does not play out in a sequential manner but emerges in fragments. The quest is to form these snippets of vision and memory into some kind of cohesive scenario. Similarly, Cournoyer’s artistry lies in the relationships between the scenarios: “It is in the process of taking these fragments, each of which has its own meaning, and linking them together so that an emotion, a guiding line, maybe even a narrative, emerges” (Roy 2012, p. 38). This approach is risky because it does not conform to the expected three-act story formula nor can it rely on simply disseminating factual information. It presupposes that the visuals may be strong enough to get the ideas across. It also enhances the sense of the project being a collection of disparate ideas loosely strung together by a connecting theme or style, similar to an anthology of cartoons. One film that employs this “fragment” approach is Marjut



Fig. 1 Spark, Andi 2012 “Tears for No Reason.” Digital paint



Fig. 2 Spark, Andi 2012 “Dodgy City.” Digital paint

Rimminen’s *I’m Not a Feminist, But...* (1986), which is an animated interpretation of drawings from a book of the same name by illustrator Christine Roche. The drawing style is varied and the vignettes do not follow a strictly narrative pattern, although there are linking elements through some of the character scenarios and the soundtrack, which includes a selection of song motifs. As curator Ruth Lingford (n.d.) notes, “they are mostly not laugh-out-loud funny, but Rimminen gives the film an entertaining pace and a lightness of touch.”

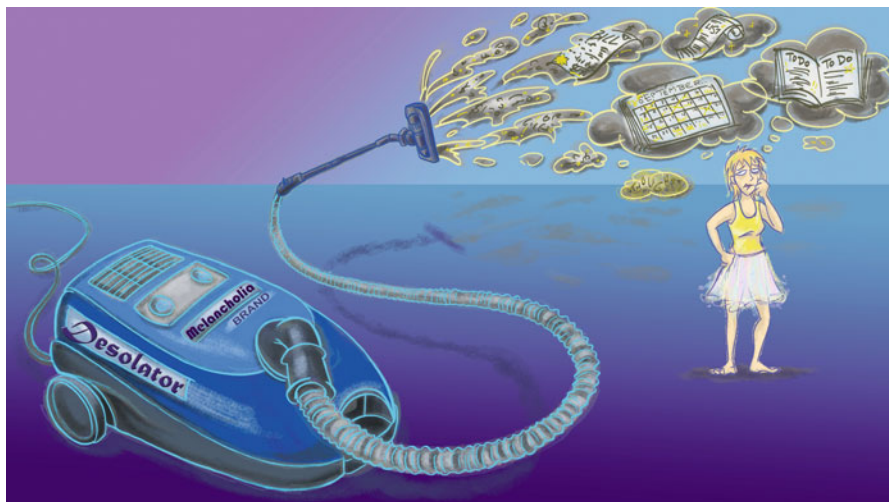


Fig. 3 Spark, Andi 2012 “Desolator.” Digital paint



Fig. 4 Spark, Andi 2012 “Tired of Life.” Digital paint

4.3 Incorporating Humor

Accordingly, the vignettes in *Coming Through* vary in style of humor; some elicit a wry chortle, and others a surprised laugh. In discussing comics and graphic novels, theorist Elisabeth El Rafaie (2012, p. 70) states that “psychoanalytic approaches to humour propose that jokes can function as a welcome release from the constant need to repress our socially unacceptable desires.” Likewise, I uphold that using

humor in this context, particularly in discussing contentious subjects like feminism, gender disparity, disability, and mental illness, offers comic relief for an audience who may be identifying with similar socially unacceptable thoughts or feelings (Furniss 1994).

Animation evokes nuances of comic timing and visual hilarity, although many of the projects of this ilk, dealing with serious issues including alienation, illnesses, depression, sexual abuse, or sexual fantasy have an unmistakable seriousness about them (e.g., Alison de Vere's *The Black Dog* [1987]; Michèle Cournoyer's *Le Chapeau* [1999]; Suzan Pitt's *Asparagus* [1979]) as well as an overtly feminist tone. Alternately, Marjane Satrapi's graphic novel *Persepolis* (2004) and the subsequent animated film of the same name (2007) deals with all of these issues with an entirely different tone. It resonates with this research approach particularly the quasi-autobiographical nature of the story appearing to be from a singular voice but created through an amalgam of many disparate incidents and the fact that the work was many years in the making. Hernandez (2010, p. 80) writes about independent animation created by women and comments on the *Persepolis* film:

Despite Satrapi's personal involvement with the story, the passing of time has helped her to reach a historical perspective, a reflection opposed to anger – the seed of extremism and fanaticism. Instead of being solemn and tragic, she wanted to appeal to all audiences through her own experiences, irony and a sense of play. . . . Thus, humour became a key weapon for exposing the absurdity of everyday situation. . . .

Elements of this double entendre humor and linguistic and visual conflation is common to contemporary internet memes. Contemporary comical slice-of-life strips, such as “Cyanide and Happiness” (2004–) with its nihilistic social commentary, Allie Brosh's (Brosh 2011) episodes in depression at *Hyperbole and a Half* (2009–13) and Nick Seluk's *The Awkward Yeti* (2011–), are closest to the kind of self-referential humor that suited this subject matter. A combination of humor and poignancy place a different spin on the way social science content may be visually articulated.

5 Affordances of Animation

Animation is a way of visualizing the invisible. It is regarded as an effective communication tool, being able to provide complicated information in a short amount of time. As Wells (1998) notes, animation uses many narrative strategies; for example, condensation and ellipsis (compressed or edited continuity); synecdoche (a small image or idea that represents the whole or more complex picture); symbolism or metaphor (recognizable signs); sound and choreography (movement, pattern, and rhythm); and penetration (ability to “see inside” and depict inner workings). As it is not reliant on linguistic comprehension or ability, animation can have narratives that are neither linear nor rational. It also proves effective in

communicating information to audiences through associative recognition of appealing characters that represent “every person” (Wells 1998, p. 122). In her introduction to *Animating the Unconscious: Desire, Sexuality and Animation*, Jayne Pilling (2012, p. 12) echoes Wells’s list of affordances:

Animation can make a unique contribution to the exploration and expression of states of mind, unconscious impulses, sexuality and sensory experience. Unrestricted by the dictates of photographic realism and traditional narrative, animation can make such experience palpable via visual imagination, metaphor, metamorphosis and highly creative use of sound.

5.1 Visualizing the Invisible

Animation is useful in showing elements of psychological vulnerability; as Wells (1998, p. 184) comments, “animation has become a vehicle by which inarticulable emotions and experiences may be expressed.” It can also portray issues that cannot be shown as real life images, whether elements of stories or testimony too painful or impossible to photograph or real life events that have not been caught on film and are incapable of adequately being recreated in live action. The quality of penetration is an important aspect of animated biographies, autobiographies, and documentaries; in particular, those that focus on mental states of mind (Mosaic Films 2015). Referencing artist Paul Klee’s famous quote: “Art is not to reproduce what we can already see, but to make visible what we cannot” (Deleuze and Guattari 1987, p. 48), I qualify the term “animation” in this context as an artist’s tool that communicates ideas.

In this spirit, using animation to tell a quasi-documentary style story has many benefits, as evidenced by Orly Yadin and Sylvie Bringas’s animated short film *Silence* (1998), which tells the story of a young holocaust survivor. In an essay published from the 2003 “Holocaust and the Moving Image” conference and subsequent book of the same name, Yadin (2005) lists several key points that demonstrate how animation can facilitate authentic communication, and particularly its compatibility with the documentary format. She writes: “Animation can be the most honest form of filmmaking . . . [This honesty] lies in the fact that the filmmaker is completely upfront about his or her intervention with the subject” (2005, p. 169). With animation, it is obvious that the images are constructed, and therefore, “if we believe the film to be true it is because we believe the intention was true” (Yadin 2005, p. 169). As she continues, “animation is less exploitative of its subjects” than live-action films because “there is no danger of being uncomfortably voyeuristic.” Moreover, she argues, using animation is “a gesture of respect towards [sensitive] subjects” (Yadin 2005, p. 169). Importantly, “animation can take the viewer to locations unreachable through conventional photography . . . [it] is very useful for saying a lot in very few frames, and saying it ambiguously enough for the audience to bring its own interpretation and experience to the screen . . . [Therefore] animated characters can seem more real than actors” (Yadin 2005, p. 170). As Yadin (2005, p. 170) observes, when we accept that we are entering an animated world, “we tend to suspend disbelief, and the animation acquires a verisimilitude that drama-

documentaries hardly ever achieve.” Utilizing animation in the social sciences field has the potential to penetrate the cognitive consciousness of the target audience.

5.2 Penetration

As noted, much of the historical literature and even contemporary audiovisual information about the issue of PND and aspects of care and support are not only extremely dry but often quite depressing themselves. Through quantitative research, I note that many of the video pieces take a documentary form, including first-person interviews and reflective anecdotes. Although these work in one sense, when watching videos, I invariably experienced a lack of connection with the person appearing on screen. Some of this was due to ethno-sociographic factors (i.e., the woman was of a different age, had a different economic status, or possessed different cultural attitudes from me), but I also found the format very boring (Brunsdon 1986). Likewise, reading through long testimonials of other people’s encounters becomes tedious and repetitive. I wanted to balance this by using the affordances of animation, such as penetration, metamorphosis, synecdoche, and other visual or symbolic cues (Wells 1998) so as to be able get *inside* the mind, beyond the corporeal, and be able to show undiluted thoughts.

The quality of “penetration,” enabling the illustrated moving image to represent what cannot be physically seen, is an important aspect of defining animated documentaries, and specifically animations that approach the issue of mental health. As part of the creative structural phase of this research approach, a contextual practice review is essential. This takes into account creative practice works, particularly animated works of a similar form and genre, to comparatively analyze in terms of content, theme, form, and function. One contemporary seminal series of works in this realm is *Animated Minds* (2003) commissioned by Mosaic Films and developed by Dr. Andy Glynne in consultation and collaboration with people who suffer from various diagnosed mental health conditions (Glynne 2003). The series of short films is based on narration of real life experiences including bipolar disorder, obsessive compulsive behavior, agoraphobia, and autism spectrum disorder. A comparative analysis content review revealed some key similarities in the use of symbol, metaphor, and form to portray myriad states of mental disruption. The *Animated Minds* series of films employ a variety of commonly used “penetrative” elements as follows: multiple layered images; deconstructed images; flickering/sped-up images; repetitive images; disconnected metamorphoses; being alone in a wide space/room/corner; images of falling, drowning, crouching (holding head); lying on a bed; being held or dangled on a hook or hanger; uncontrolled movement; hole in body/penetration beneath skin; symbols and diagrams; and words in text. Through this connective research, many of these symbols and metaphors are also employed in the *Coming Through* series as a way of shortcutting the additional visual vocabulary required to read the project. Using these techniques provides an opportunity to enhance the dissemination of extended knowledge into medical and scientific areas and the social sciences fields.

6 Conclusion and Future Directions

In developing original creative responses to the experience of PND, the work contributes to the body of knowledge in this field, both from a social service viewpoint and as an expressive model for cross-disciplinary visual and screen arts practice associated with the animation medium. On review of the “multi-methods” methodology used throughout this research, I also endeavor to contribute a framework for approaching visual art-based research in the humanities or social health and social sciences fields (see also ► [Chap. 64, “Creative Insight Method Through Arts-Based Research”](#)). The studio component is essentially practice-based, contributing my own work to the field of knowledge, which developed from a heuristic approach evolving from deep immersion and engagement with the subject matter and developing a response using tacit knowledge and intuition. This also would be considered autoethnographic in the way I tell my own story (see also ► [Chap. 30, “Autoethnography”](#)). However, it also crosses into the area of narrative enquiry in terms of “re-storying” by using anecdotes and interpretations of others’ similar experiences of PND (see also ► [Chap. 24, “Narrative Research”](#)). An action research methodology also contributes a key factor in this approach through a systematic feedback loop on analysis of the practice-based work in connection with an analysis of medical and scientific data or knowledge – in this case, tracking the content of my animated vignettes to the recognized and acknowledged list of symptoms of PND. Action research also includes the reflective feedback loop embodied in the critical reflection and iterative production (see also ► [Chap. 17, “Community-Based Participatory Action Research”](#)). This also incorporates a phenomenological methodology, not only through the subjective, experiential, self-descriptive content but also through the approach to the actual animating process utilizing concepts of flow and risk in the “happy accident”. This research approach includes practice-led methodologies, discussing the nature of artistic practice which also includes content analysis, process analysis and discourse analysis surrounding other key practitioners works while considering this singular overarching practice as a case study to exemplify this methodological approach. A multimethod approach combining elements across the creative and sciences fields affords possibilities for deeper understanding of the contexts and content in research projects.

Further developments utilizing this approach may include a more defined structure in establishing clinical or diagnostic evidence, incorporating a stronger feedback loop from medical practitioners in the initial stages of the creative practice. It is also desirable to include further examples and anecdotes from patients or associated people experiencing the targeted condition. Prospective projects in this genre remain focused on the lived-experience of an illness or situation. Some examples are about the experience of being diagnosed with cancer and breast or reproductive organ cancer specifically. Highlighting this area maintains the focus on the under-represented demographic of the adult female, particularly in how mature women are shown in animation forms.

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Researching Underage Sex Work: Dynamic Risk, Responding Sensitive, and Protecting Participants and Researchers

121

Natalie Thorburn

Contents

1	Introduction	2112
1.1	What Constitutes “Sensitive” Research?	2112
1.2	Researching Sensitive: Using Feminist Principles	2112
1.3	The Dynamic Nature of Risk	2113
2	Case Study: Researching Survivors of Sexual Exploitation	2114
2.1	Overview of the Research Design	2114
2.2	Agency and Consent	2115
2.3	Involving Gatekeepers	2115
2.4	Building the Research Relationship	2116
2.5	Maintaining Confidentiality Despite Illegality	2119
2.6	Considering Context: Personal, Social, and Political	2119
2.7	Isolation and Responding to Danger	2119
2.8	Trust-Building and Researcher Vulnerability	2120
2.9	Managing Postproject Interest	2121
3	Strategies for Engaging with Vulnerable Populations	2122
3.1	Agency Support and Cooperation	2122
3.2	Importance of Interpersonal Approaches	2122
3.3	Knowledge of Trauma	2122
3.4	Risk Management in Advance	2123
4	Conclusion and Future Directions	2123
	References	2124

Abstract

Navigating ethical issues solely involving wholly competent adults who are physically safe and who play agentive roles in negotiating their social environments is often rife with difficulty. Navigating these ethical issues with human participants who are underage; or whose cognitive-emotional processes are potentially impacted by

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previous trauma; or who lack autonomy, freedom, or basic safety makes the preparation and execution stages of research exponentially more difficult. This chapter recounts the challenges inherent in the author's experience of conducting research with adolescent sex workers, many of whom have complex trauma histories. It goes on to discuss the dynamic nature of risk as it relates to research with vulnerable populations, particularly in regard to physical safety, emotional and psychological safety, consent, confidentiality, and interpersonal power within the research relationship. Finally, methods of identifying and managing these risks are discussed.

Keywords

Exploitation · Feminist · Methodology · Prostitution · Sensitive research · Victims · Violence · Vulnerability

1 Introduction

1.1 What Constitutes “Sensitive” Research?

Whether an interview topic is considered “sensitive” depends on how it is regarded within social and cultural norms (McCosker et al. 2001). Lee (1993) argues that the three topics that are typically considered sensitive are stressful or personal events such as sexual abuse, identity issues that are stigmatizing, and topics with political overtones that may be invite controversy. The involvement of adolescents in sex work, with its nuances of sexual violence, stigmatization, and political positioning, can be seen to contain all three elements. However, topics considered “sensitive” to researchers might not necessarily be viewed as such by prospective participants, as many report positive outcomes resulting from their opportunities to speak freely and in a safe environment about these personal experiences (McCosker 1995). Sieber and Stanley (1988) propose an alternative to the conventional conceptualization of “sensitive” studies, arguing that sensitive research is instead research that poses potential adverse complications for the target group, either through the act of participating in research or through the outcomes arising from the research product. This is echoed by Lee's (1993) argument that research sensitivity is determined by the level of threat inherent in participating, and notes that this threat does not apply only to participants, but to anyone directly or indirectly involved in the research (see also Liamputtong 2007). Violence against women, however, fits naturally into the category of sensitive research (Fontes 2004), as it contains threats to both physical and emotional safety, and also contains themes of intimacy, sexual integrity, and personal power (Lee and Renzetti 1990; Liamputtong 2007).

1.2 Researching Sensitive: Using Feminist Principles

Given that the use of underage people in sex work clearly represents a type of gender-based violence, with perpetrators being typically male and victims typically female

and/or children, the use of a feminist research methodology is fitting. Feminist research is centered on unmasking the lived experiences of women, and in particular, women whose expressions of their experiences have historically been silenced (Ezzy 2002; Liamputtong 2007; Olesen 2000; Sands 2004; see also ► Chap. 119, “Feminist Dilemmas in Researching Women’s Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise”). Contiguous goals include the consideration of women in the context of the entirety of their social lives and individual situations, with reference to the influence of economic status, class, sexuality, suppression of identity, and most of all, gender (Darlington 1993; Olesen 2000). Furthermore, it requires the researcher’s commitment to furthering the interests of women involved with the study, taking into account the wider policy context of both the stated problem and the research findings, and acknowledging their subjective positioning with regard to their background, worldview, racial, sexual, and gender identity, and social influences (Alston and Bowles 2003).

A wealth of literature supports the conclusion that, if done well, participants are likely to find their participation in sensitive research satisfying and beneficial (Martin et al. 2001; Rabenhorst 2006; Campbell et al. 2009; Edwards et al. 2009). Four issues central to doing sensitive research benevolently are identified by McCosker et al. (2001); namely, accurately defining the topic, accessing participants, avoiding concealment and distrust within the researcher-participant relationship, and actively promoting safety. While literature concerning the practical issues of safety in research into experiences of violence is scarce (McCosker et al. 2001), some studies focus on the psychological safety of the researcher and/or participants (see Burr 1996; Young 1997; Rowling 1999; Dickson-Swift et al. 2008; Hom and Woods 2013). Strategies suggested to mitigate the risks of psychological harm and triggering of painful emotions for participants include building rapport prior to the interview, taking steps to preserve confidentiality and anonymity if there is potential danger, ensuring researchers have appropriate professional backgrounds that enable them to manage sensitive disclosures, providing information about options for crisis counselling and on-going support, and using debriefing to assess immediate impacts (McCosker et al. 2001; Liamputtong 2007). This case study will, therefore, set out some of the interview methods, contact processes, and risk management techniques used with the adolescent sex workers who participated in the research.

1.3 The Dynamic Nature of Risk

Mulla and Hlavka (2011) express their discomfort with the generalization of all victims of violence into a particular “class” of vulnerable participants, suggesting that victimhood, or victim status, is a fluid state and does not invariably distort levels of safety or risk involved in interviewing survivors of violence. The concept of “risk” to participants should be considered within the contexts of social position, culture, and environment; for example, a participant whose daily life is saturated by “risk” may view the potential for psychological distress to occur during an interview as minor in comparison (Miller et al. 2006). The concept of vulnerability must, therefore, be fluid, and assessed on a case-by-case basis, with care taken not to impute preconceived notions of victimhood or vulnerability onto prospective participants, thereby further disempowering them

(Alcoff and Gray 1993; Lamb 1999). Mulla and Hlavka (2011) thus position participants, like researchers, as “moral agents,” who should be given sufficient information and options to be able to make decisions in a manner similar to the decision-making processes used in consent decisions as medical or legal subjects, arguing that to assume a level of incapacity following victimization may in itself be harmful both to the participant and to the researcher. Moreover, this principle of adhering to self-defined notions of competence and consent is not solely restricted to the recruitment and consent stages; rather, personal narratives should also be treated with integrity throughout the data analysis and discussion stages, to mitigate the potential for secondary violence that “arises when victims, subjected to epistemic categories and understandings that do not fully encapsulate their experiences, do not recognize themselves in the research product” (Mulla 2008, p. 1514). Accordingly, Clark and Walker (2011) argue that researchers should address risk considerations at each stage of research, from explication of the research purpose to decisions about publication. At the same time, research with any supposed “vulnerable” group must be both intentional and reflexive, and privilege both process and outcome (Fonow and Cook 1991; Stanley and Wise 1993).

2 Case Study: Researching Survivors of Sexual Exploitation

2.1 Overview of the Research Design

The aim of the research was to explore participants’ experiences of having been involved in sex work as children or young people under the age of 18. Specifically, it sought to find out what the early life experiences and current social situations were of adolescent sex workers, how they understood and organized their interactions with their clients, and how they experienced interventions from formal services.

While initially sourcing ten participants, two interviews were terminated soon after beginning due to explicit risk to participants. Consequently, only eight participants completed their interviews. While more would have been ideal, eight is still a robust number given the depth of the each interview and the challenges inherent in accessing a population that is transient, typically shrouded in secrecy, and often suspicious of any professional involvement. The aim was not to generalize findings to all adolescents involved with underage sex work, but rather to explore and increase understanding of the experiences of the sample and the policy and practice implications for young people who might share these experiences. The eight participants were all aged 16–20, and had been involved with USW prior to turning 18, with all participants beginning formal sex work between the ages of 12 and 16.

The selection of participants aged 20 and under only, despite the limitation this imposed on sample size, was enforced so that the experiences analyzed would be relevant to current policy frameworks and practitioner initiatives. In addition, due to the reformulation and recontextualization that retrospective remembering of experiences invariably involves, the perspectives of adolescents were considered more likely to provide insight into the meanings they attributed to their experiences within a shorter time-frame of these occurring.

2.2 Agency and Consent

While emotionality throughout the interviews was by no means a unique experience, it did not indubitably indicate lack of agency or impaired ability to consent to being part of the research. However, this constituted a principal consideration, and being accustomed to working with survivors of trauma enabled me to differentiate between emotional states that demonstrated healthy responses to the recall of traumatic events, and those that appeared to threaten participants' emotional equilibrium beyond a level conducive to giving continuous and meaningful consent. Threats to consent were characterized by blankness, inability to recall, unquestioning compliance, and needing to prompt responses. These signs were useful in letting me know that the person may be moving into unhealthy remembering, and, accordingly, that it was time to phase out of interviewing and into a supportive role. In addition, on starting the study, a key concern was whether participants' autonomy may be inhibited by abusive or controlling situations; however, while several disclosed this occurring in the past, only two (one of whom did not complete the interview) had dominant themes of being controlled in the present throughout her interview. On reflection, this is likely to be associated with the method of recruitment; the act of responding to a recruitment flyer and taking the initiative to speak to a researcher for a small voucher incentive (and, as it was later discovered, the chance to tell an attentive listener the full story) indicates a level of agency and choice that is unlikely to occur within a context of control.

2.3 Involving Gatekeepers

As previously discussed, the question of whether to involve parents to give consent on behalf of adolescents, who may have experiences of trauma unknown to parents or caregivers, poses a significant methodological dilemma (Campbell et al. 2014). Limiting samples to only those whose caregivers are aware of their histories of victimization excludes an important subgroup of prospective participants. Campbell et al. (2014) propose a prospective design, where invitations to participate are extended by a third-party organization providing services. However, this too has risks: young people may be unintentionally coerced into participation if they are recruited directly by somebody within a service they are receiving help from (Campbell and Dienemann 2001). To this end, Edleson and Bible (2001) suggest developing relationships between advocates and researchers to enable ethical access to participants. Researchers seeking participants in violence against women research may also solicit participation through recruitment flyers at helping services, counseling clinics, Laundromats, childcare centers, and agency waiting rooms to reduce the potential for any coercion, as this method requires participants to initiate contact rather than the reverse (Fontes 2004).

Accordingly, the first step in the recruitment of participants involved approaching agencies known to have contact with the population group and requesting that they display recruitment flyers at their premises. However, the relationships

between potential professional intermediaries or gatekeepers for the population being researched are not always straightforward. There was a less than enthusiastic response than I had hoped for from the agencies I approached to display my flyers. Many did not respond to any attempts to contact them, and the Family Planning Association, from which I had anticipated a positive response, declined my request to have recruitment flyers displayed in their reception areas, citing differences in values and implied judgment of clients evident in the short brief I gave them. This was apparently due to the explanation included in the brief of the legal framework surrounding USW, which included the clarification that according to New Zealand legislation, “clients” are legally offenders when they purchase sexual services from adolescents under 18.

However, certain organizations and practitioners helped not only to facilitate access but also to develop lines of questioning (or appropriate terminology) to promote communication between researcher and participant. The New Zealand Prostitutes’ Collective (NZPC) and Social Workers in Schools (SWiS) were invaluable for these purposes. The professionals who did become involved in some way with the project, whether to offer advice or assistance, were typically those who had been individually contacted and met with in person – fulfilling, in short, the “gatekeeper” role judiciously. Conversely, those who were sent the standard email appeared to be more averse to the idea of being seen to endorse research – and a researcher – with which they were unfamiliar.

2.4 Building the Research Relationship

Another chief concern was the extent to which participants would feel able to talk freely to someone who was effectively an untrusted stranger. Paradoxically, given the dominant themes of reluctance to engage with professionals that featured in all of the interviews, this problem did not eventuate. However, strategies designed to mitigate the potential for this to occur centered on methods of contact – I considered it imperative to have the opportunity to exchange text messages with, talk on the phone to, or have a “warm-up” period with participants, in order to allay any concerns they may have about being identified, being judged, or being emotionally triggered by the interviews. Correspondingly, while I had several topics on my interview agenda, the interviews were largely participant-directed, as this was felt to increase their level of control. Given the relative likelihood of them having experienced multiple incidents of having control stripped from them by abusive others in the past, I wanted to minimize the risk of replicating the feelings associated with those experiences. While the reasons behind the ease with which the interviews progressed are difficult to isolate, it is likely that maximizing participants’ agency throughout the process is associated with their willingness to engage.

As suggested by McCosker et al. (2001) and Dworski-Riggs and Langhout (2010), the relational strategies used with participants are instrumental in facilitating openness, comfort, and a sense of safety. There were three (often extremely simple in

practice) primary interpersonal considerations I used while conducting interviews with adolescent sex workers – participant pacing, nonjudgmental questioning, and maintaining a therapeutic presence. The first consideration, participant pacing, has three intersecting objectives: it allows raw data to emerge spontaneously based on participants’ perceptions of what is important, thereby privileging their narratives over those of the researcher and preserving the integrity of data; it allows participants to be in control of the process, affording them additional agency; and it avoids retraumatization by consistently presenting disclosure of abuse or marginalizing experiences as optional. It was not entirely participant-led, as I offered guidance and asked questions at times, but the depth and breadth of answers was left up to participants. For example:

Natalie: “We can start wherever you like – perhaps how you came to be involved in sex work?”

Participant: “Do you want just the sex stuff, or all the stuff?”

Natalie: “It’s up to you – however much you’d like to tell me.”

Participant: Okay. Well, I . . . it’s hard to know where to start really. Maybe I’ll start by telling you a bit about the sex industry and then give you the background later, like why I did it”

Natalie: “You’ve mentioned escape a couple of times, can you tell me a bit more about that?”

Participant: “Uhhh yup . . . I’ll try. I just. . . There were times when . . . oh, it’s so hard to explain, sorry!”

Natalie: “You’re doing great, take your time.”

Participant: “There was . . . there were times when I just felt like if I stayed still too long it would be . . . too hard to deal with. The feelings I was having of just not being, not being . . . good enough I guess? Not being cared for, not having family to go back to”

The second consideration, nonjudgmental questioning, was a strategy I saw as essential to avoid imputing judgment through my participation in the conversation. Literature into underage sex work highlights both push and pull factors; I needed to avoid texturing their experiences for them by assuming they had experienced any particular event negatively. This was also integral to avoiding shaming or embarrassing participants. My approach, therefore, was to follow the lead of participants – if they used negative language to denote an experience, so did I.

Participant: “. . . it was pretty nasty shit.”

Natalie: “You mentioned the nasty shit that happened. How’d you cope with that?”

Participant: “I don’t know, sometimes. Like, sometimes I wonder why.”

Natalie: “Why what?”

- Participant:** “Like, why I did it . . . like, I see girls talking about it, like I was with a couple of people and we were driving through town one night, and they were yelling out to prostitutes. . . like, wow, I used to do that. . .”
- Natalie:** “So you saw other people doing what you used to do? How did that feel?”
- Participant:** “I don’t know, like . . . some people are so judgmental!”
- Natalie:** “And when you do ask yourself why, what kind of answers do you come up with?”
- Participant:** “Like, my big answer for it is just because I was lonely. I felt unwanted. And all my social group were doing it, and I felt wanted.”
- Natalie:** “When you cut yourself, what did that do for you?”
- Participant:** “It, it sounds crazy, but it helped. It made me feel something and I was so switched off. I also hated my body. It was kind of like punishing myself, cos for such a long time I felt like it was my fault. If I had been different, or done something different, it wouldn’t have happened.”
- Natalie:** “Really?”
- Participant:** “Ummm, I don’t know. Maybe? Um, I . . . I should’ve known better. Or not been so dumb. Or, like, told someone, then maybe I wouldn’t have held it all on my own in my mind for so long.”
- Natalie:** “What was it like keeping it secret?”
- Participant:** “Um, shitty. It was really hard but I just couldn’t voice it. I was too scared people would see it in my face, and would know.”

The final consideration – maintaining a therapeutic presence – necessitated therapeutic microskills such as reflecting back emotions, validating experiences, and gently challenging narratives of self-blame. My reasons for this were two-fold: these techniques engendered an honesty and depth that may not have been otherwise possible and which added a raw richness to the data, but, more importantly, because not to do so in the face of emotional vulnerability of young people would have felt unacceptably divergent to my professional training and values.

- Participant:** “So when I had those feelings, or when I was around guys who, umm, if they, you know, there was something about them that made me feel unsafe, I would leave. Or if I felt like someone was going to reject me or not like me, I would leave. That way I wouldn’t get hurt. Like hurt emotionally.”
- Natalie:** “That sounds really rough and really scary. Would you have liked someone to intervene?”
- Participant:** “Yes! But I couldn’t ask them to. I thought if I told someone how I was feeling, or like what I’d been doing, they’d just be disgusted, and not like me.”
- Natalie:** “It seems like you coped really well in a pretty hard situation.”

2.5 Maintaining Confidentiality Despite Illegality

Given that the participants in the study were legally the victims of crime and were disclosing information that could have the propensity to identify their offenders or the nature of the offending, steps were taken to minimize the risk to participants, and to a lesser extent, the risks to me as the researcher. These included encouraging the participant to use an alias, and not collecting any identifying demographic information from participants. The rationale behind this stemmed from two concerns: firstly, the concern that if transcripts or consent forms were ever compromised, participants' safety was less likely to be at risk; and secondly, if I was later asked questions about disclosures of illegal activity, I could answer truthfully without breaching participants' anonymity. This turned out to be propitious, as subsequent media attention regarding the alleged involvement of police officers with underage sex workers in the study prompted investigation by the Independent Police Complaints Authority. The combination of participant-led interview data, the use of aliases, and not collecting demographic information meant that I could truthfully answer Police questions without having to make decisions about either withholding information or compromising researcher ethics pertaining to confidentiality.

2.6 Considering Context: Personal, Social, and Political

New Zealand does have comprehensive laws prohibiting the use of children and young people under 18 years of age in sex work; however, the extent to which these are actively enforced and accompanied by supportive measures for survivors is debatable. Further, the laws did not, at that time, recognize the sale of children or young people for sexual purposes occurring within a context of organized crime as trafficking, and participants displayed a predictable lack of faith in statutory agencies to protect and support them when considering whether to report violent crimes. This limited the options available to participants, as existing services – many of which they were already familiar with – were unlikely to meet their range of needs, and most had already developed negative outcome expectations from their interactions with statutory agencies. Several expressed the belief that if there had been an appropriate service that they perceived as supportive rather than punitive, and did not pose a threat to their continued autonomy, they would have willingly engaged with it. Unfortunately, in the absence of political will, professional knowledge, or local resources for such an issue, avenues for external assistance for participants were extremely limited, which largely negated the role separation of “researcher” and “practitioner.”

2.7 Isolation and Responding to Danger

It has been acknowledged that an immediate response by specialist services and/or law enforcement following victim-survivors' disclosures of being harmed in a

context of sexual exploitation is imperative to limit further harm (Pearce 2009; Jordan et al. 2013). However, in lieu of formal services set up especially for this population group, or consent to contact Police when a participant disclosed being at imminent risk of harm, the person receiving the disclosure is, by necessity, cast into the position of needing to act to promote the victim-survivor's safety. In some situations, this leads to an on-the-spot decision about whether to reject the helping role in favor of assuring safety (both the participant's and the researcher's), and acting as a practitioner, albeit informally, to address immediate psychological and physical needs and to facilitate access to services – knowing that with some participants' complex, transient backgrounds, the opportunity to facilitate intervention is unlikely to reoccur quickly.

Two participants disclosed that they were significantly at risk of imminent harm during interviews. One of these risks was to the participant's physical integrity; the other to their emotional well-being as talking (although directed by her) elicited traumatic memories that appeared to prompt traumatic dissociation and, accordingly, required both immediate support and provisions for longer-term help. While both had already given immensely rich data pertaining to serious elements of other-controlled underage sex work not captured by other participants, the seriousness of their risks necessitated data collection becoming secondary to safety planning. Both interviews were, therefore, stopped and the recordings deleted. For the first situation of risk, Police were engaged to secure safety; for the second, psychological first aid was used to stabilize her immediate crisis state before accessing specialist services for follow up. Unfortunately, because of the agreement that contact between participants and I would only be initiated by them for safety reasons, I was unable to follow up on either of their situations for my own peace of mind. However, both situations gave me valuable experience in recognizing situations where risk intersects with participation in research, and managing this risk by prioritizing the wellness of participants.

2.8 Trust-Building and Researcher Vulnerability

Gaining the trust of victim-survivors often necessitates some level of self-disclosure (Ahrens et al. 2007; Campbell et al. 2010), and if this is deemed appropriate by the researcher, this may be premised on shared experiences; for example, addiction, sexual assault history, mental health challenges, parenting, or domestic violence (Ceglowski 2000; Kanuha 2000; Hayman et al. 2012; Campbell et al. 2014; Reddy et al. 2006). At the time, some reciprocal self-disclosure seemed imperative, in order to acknowledge the disclosures of the victim-survivor. However, in some instances, this information gave power to third parties who were secondarily privy to these disclosures, which was potentially dangerous given the contentious nature of the research and the possible ramifications of exposure for anyone profiting from sexual exploitation. After the discovery of the resulting safety threats, I then learned to steer such self-disclosure toward innocuous experiences (for instance, anxiety prior to

public speaking, or similarly “safe” vulnerabilities) that could not be subsequently exploited for the secondary listener’s gain.

2.9 Managing Postproject Interest

Most studies propose techniques to maximize safety and focus on the researcher’s stance and approach within interviews, the methods employed to coordinate meetings while safeguarding both the researcher and participant from harm, and strategies to increase participants’ perceptions of their safety during their involvement (see May 2001; Shuy 2002; Northcutt and McCoy 2004; Sullivan and Cain 2004; Baker 2005; Stringer and Simmons 2014). However, such studies rarely expound on researchers’ strategies to mitigate the risks and vulnerabilities arising from informal contact following publication, or on the enmeshment between researchers’ academic, professional, and personal lives as they become involved with inherently dangerous phenomena. Following my research into underage sex work and subsequent media coverage, I received unsolicited contact from a range of people, including sex workers, people who had been sexually exploited during childhood, and people who spoke of being controlled by crime organizations. Given the number of messages via social media being received, and the range of motivations behind them, it was difficult to identify which of these individuals might be motivated to make contact with me because of their own experiences, and which were simply bystanders interested in the research findings. In some cases, young women who initiated contact had social media accounts indicating that they were feminist activists; in other words, whose public presence was consistent with that of other interested parties who contacted me with a view to engaging in academic debate. Some later revealed their status as victim-survivors of sexual exploitation, in either opportunistic or organized contexts. In other instances, the perception of me as an apparently trusted advocate as a result of my previous research results in girls obtaining my contact details and giving me information. Both situations resulted in ethical dilemmas about what and when to report to Police that extended well beyond the length of the initial project. The informal nature of this contact exacerbated the complexities of ethical decision-making; I was no longer protected by the limitations of the “researcher role” and the accompanying luxury of having clearly defined criteria and procedures for responding to crises, threats, and disclosures of harm. Further, as a registered social worker, I had a mandated obligation to report situations where children are at risk of harm, meaning that any stories implying the abuse of anyone under the age of 18 presented an immediate dilemma of whether or not to report. The implications of this mandate were far from straightforward; often the allusions to underage involvement of victims were vague and lacking in any kind of detail that could be realistically reported to statutory agencies. These decisions consequently end up being almost entirely subjective, without the safeguards inherent in obtaining secondary input. In this project, these dilemmas were managed by facilitating relationships with Police and passing on information that involved

anyone currently underage, while also making efforts to ensure that they understood the complexities of situations and the need to proceed sensitively.

3 Strategies for Engaging with Vulnerable Populations

3.1 Agency Support and Cooperation

As demonstrated, gatekeepers are instrumental in enabling access to participants, and in guiding the researcher to communicate with a population group that may be unfamiliar or hard to reach. In the event that a participant requires help, the easiest way to facilitate this is to have already established avenues for assistance. By creating relationships with helping professions and with police, the search for appropriate services may be expedited, offering peace of mind and additional safety when confronted with complex risks. This may be particularly beneficial once the research is completed, but unsolicited contact, information, and reports of harm that require external help continue.

3.2 Importance of Interpersonal Approaches

Talking about trauma has the potential to be retraumatizing, and participants in research projects focusing on marginalization or interpersonal violence have often lived through events they experienced as traumatic. Strategies to mediate the risk of reinforcing feelings associated with this trauma are suggested in the literature, such as building rapport through initial phone calls and emails, demonstrating empathy throughout engagement, using appropriate self-disclosure, and using open-ended but sensitively phrased questions (Enosh and Buchbinder 2005; Peters et al. 2008). The risk of exacerbating distress through discussion about sensitive experiences will also be partly mitigated by allowing participants to pace the interviews.

Victims of interpersonal violence have often been disempowered, silenced, and controlled. Repositioning the balance of power to lie with the participant, rather than researcher, helps to avoid re-experiencing dynamics of control as a result of the research (Northcutt and McCoy 2004). Baker (2005) suggests also paying attention to issues such as dress style, speech, and professionalism as potential barriers to engagement. Participants should be afforded the right to tell their stories in their own words without this process being dominated by the interviewer (May 2001; Shuy 2002). Appropriate self-disclosure can also be used, ideally centering on vulnerabilities that will not compromise either party if they are passed on.

3.3 Knowledge of Trauma

It became apparent when reviewing similar previous studies that participants in this study were likely to have multiple and intersecting experiences of trauma. This has

implications for interviewing: participants should have control over what experiences they choose to disclose, and control the pace of such disclosures, to avoid being overwhelmed or feeling coerced into sharing intensely personal experiences.

3.4 Risk Management in Advance

Obviously, it is impossible to plan for every contingency – participants, like all individuals, are complex beings and present multifaceted and interweaving issues and experiences. However, some of the basic (and likely) safety needs can be prepared for – for this group, some of the anticipated needs included being at risk from boyfriends, gang members, or pimps, both in general and as a result of them discovering the participants' involvement in the study; retraumatization through discussion of physical and sexual violence histories; possible familial violence or homelessness; and the risk of disclosure involving children and young people being harmed, necessitating police notification. Accordingly, step-by-step plans were made for these situations, although they needed to be adapted, updated, and reformulated in conjunction with the participant at the time of risk disclosure, in recognition of the participant's right to agency (in other words, a say in what safety measures should be taken), and complicating factors (for instance, traumatic dissociation). As recommended by Clark and Walker (2011) and Duong (2015), these risk management plans should encompass potential risks arising at each stage of the research process, from explanation of the project, actual contact, and representation of the findings. This risk management plan should incorporate managing the aftermath of the research, as subsequent public interest in research into controversial social conditions is unlikely to be a unique experience.

4 Conclusion and Future Directions

Ultimately, researching violence against women, and especially violence against women that occurs within a context of organized crime, is fraught with risk. In my experience, this level of risk was elevated by the absence of public recognition and the consequent lack of adequate service provision for this group, leading to immense pressure to blur professional, personal, and researcher boundaries. It is therefore critical to put a number of safeguards in place and to plan for contingencies that may occur during or following face-to-face contact with participants or prospective participants, including obvious or physical risks, the potential for interviewing style to mitigate or heighten participants' personal vulnerabilities, the possibility of being positioned as a first responder to disclosures of imminent risks of harm, and the prospect of on-going or additional contact after closure of the project. However, these risks can be principally managed by due consideration of the likelihood of prior experiences and corresponding adjustment to methods of contact, relationship building, and interviewing, and by the institution of a robust plan to manage threats of safety at each stage. Finally, the paramountcy of facilitating a researcher-participant

relationship that induces participant trust, comfort, and nonjudgment cannot be overstated. This relationship fulfils dual functions in sensitive research projects: it establishes the infrastructure from which rich and sincere data can emerge, and it fulfils an ethical imperative in the quest to gain such data while causing minimal harm and maximum benefit to potentially vulnerable participants.

The increasingly diverse methods of participant recruitment offered by social media and corresponding potential for participants to use both anonymity and deception present a range of unprecedented ethical issues. The discussion in this chapter is therefore hoped to provide some insight into the potential issues inherent in new methods of contact and unorthodox research contexts when researching sensitive topics, and provide some strategies for ethical engagement that safeguard both the researcher and participant.

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The Internet and Research Methods in the Study of Sex Research: Investigating the Good, the Bad, and the (Un)ethical

122

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Contents

1	Introduction	2128
2	The Ethics of Studying Sex	2128
3	Secondary Research: The Internet and Desk Research	2130
4	Primary Research: Online Materials	2132
5	Primary Research: The Internet and Participant Recruitment	2133
6	Primary Research: The Internet and Sexual Subculture Participant Recruitment	2135
7	Primary Research: Online Ethnography	2137
8	The Internet and Deceptive Responses	2138
9	The Internet and Truthful Responses	2140
10	Conclusion and Future Directions	2140
	References	2141

Abstract

The Internet has thoroughly revolutionized sex. On an individual level, the technology has become a key source in exploring sexuality, researching sexual interests, and participating in erotic activity, both vicariously and potentially even physically. For scholars, the Internet has given effortless access to academic databases and archives, to social media sites and public diaries, and notably to a world of possible research participants, in turn dramatically altering the ways sex gets studied. This chapter outlines, analyzes, and problematizes the use of the Internet in sex research, drawing on a wide range of literature on research ethics as well as my own background as a sex researcher, an author of a range of recent material specifically about the Internet, a supervisor of several dissertations on new media, and a long-time member of my university's human ethics committee.

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1 Introduction

The Internet has thoroughly revolutionized sex. On an individual level, the technology has become a key source in exploring sexuality, researching sexual interests, and participating in erotic activity, both vicariously and potentially even physically (Rosewarne 2011, 2015, 2016a). For scholars, the Internet has given effortless access to academic databases and archives, to social media sites and public diaries, and notably to a world of possible research participants, in turn dramatically altering the ways sex gets studied.

This chapter outlines, analyzes, and problematizes the use of the Internet in sex research. I begin with a brief discussion of the ethics of researching sex and, more specifically, the role of the Internet in this endeavor. I follow with an examination of the Internet as a tool in secondary source data collection. I explore the technology's use in recruiting research participants: both in general via the utilization of an easy means to broadcast requests, and then, more specifically in targeting the hard-to-reach, notably members of sexual subcultures. Lastly, the role of the Internet as shaping research participation is examined: both its usefulness in concealing identity – and thus potentially fostering enhanced honesty – as well as the deception potential that such anonymity fosters.

This chapter draws on a wide range of literature on research ethics as well as my own experience as a sex researcher, an author of a range of recent material specifically about the Internet (Rosewarne 2016a, b, c), a supervisor of several dissertations on new media, and a member of my university's human ethics committee since 2010.

2 The Ethics of Studying Sex

Sex researcher Leonore Tiefer wrote a 1991 essay criticizing the persistent call from within the discipline for “rigor” in sexology. Tiefer considers that this as, at least partly, a ham-fisted response to the struggle sexology has had in securing legitimacy, and is a call designed to somehow counter the tireless “yes, it’s interesting, but it isn’t science” criticisms of sex research (Tiefer 1991, p. 596). Numerous theorists in fact have spotlighted the struggle that sexology has had in being recognized as legitimate in a relatively conservative academic environment (Irvine 1990; Waynberg 2009). Many of the underpinnings of this struggle – i.e., suspicions about the prurient interests of researchers (Rosewarne 2011; Thomas 2016), and the widespread belief that sex is a private matter and a topic in bad taste to casually discuss (Rosewarne 2013) – are the very reasons why such research is often considered problematic:

asking people about their sex lives, fantasies, and attitudes has long been considered sleazy and invasive, if not also *low-brow*, in the academy.

Research – particularly the kind that involves humans – is under permanent pressure to be ethical. Ethics committees at universities and hospitals go to great lengths to ensure that safeguards are in place to protect both participants and researchers (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). Such committees exist to thwart troublesome or unworkable research and to provide guidance to scholars on how to improve research design. The geographer Clare Madge (2007) discussed the conduct of human research online and summarized the five key areas prioritized in research ethics policies: informed consent, confidentiality, privacy, debriefing, and netiquette. While these concerns are relevant for any human research project, each factor – notably consent, confidentiality, and privacy – have additional relevance in sex research. For all those reasons that sex is considered private, embarrassing and difficult to talk about are the very reasons that special care needs to be taken when conducting sex research, notably when consent, confidentiality, and privacy have heightened relevance. In a world where judgment, marginalization, and criminalization often occur as a result of exposed sexual interests, research into sex necessitates that effort goes into both comprehensively informing project participants and – as far as possible – ensuring their confidentiality. It should be noted that achieving these things has additional burdens online. Social researchers Jesse Bach and Jennifer Dohy (2015, p. 319), for example, identified the troubles they encountered in establishing consent while using the Internet to study human trafficking: “informed consent, is exceedingly difficult when researching online commercial sex advertisements due to the clandestine nature of the crime and the environments that host it.”

It has been contended that scholars undertaking online sex research are not uniquely burdened in regard to ethics, but just need to be mindful of the ethical demands placed on human research of *any* kind and the necessity to keep abreast of best practice around sex research (Wagner et al. 2004; Dewey and Zheng 2013; see ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). It is, however, worth questioning whether conducting such research online creates any additional ethical quandaries, a topic addressed by numerous scholars (Binik et al. 1999; Madge 2007). Madge (2007, p. 656), for example, summarizes the existing literature, identifying:

It has been suggested that online research ethics raise many interesting debates as the computer stands ‘betwixt and between’ categories of alive/not alive, public/private, published/non-published, writing/speech, interpersonal/mass communication and identified/anonymous.

Here, Madge spotlights the complexity of online interactions whereby ideas about geography, privacy, and identity have different meanings online than off. Should the identities, for example, encountered online be considered “real”? Should statements made in social media or in a blog be treated as on the public record? Are exchanges made in chatrooms considered private or public conversations? As Madge highlights, medium specificities need to be kept in mind. Studying sex online also

necessitates a rethink of some unique practical and theoretical factors relating to ethics. Binik et al. (1999, p. 82) for example, question: “Are paper and electronic consent forms interchangeable? Can we promise anonymity and confidentiality on the Internet?” The authors extend their concerns to the determination of age: “The researcher probably cannot use the Internet to verify the minor’s real circumstances and responses to the research (e.g., whether they are actually safe from harm as a result of participation)” (Binik et al. 1999, pp. 84–85). While Binik and colleagues posed these questions in 1999 – in the earliest days of mainstream Internet use – they nonetheless remain concerns relevant to researchers today.

Discussed later in this chapter is virtual ethnography: of relocating fieldwork to an online space. While indeed, such research boasts appeals, the idea of a researcher “lurking” in online spaces, without making their presence known, conflicts with a range of ethical principles established by research bodies. Binik et al. (1999, p. 83), for example, reference the American Psychological Association whose guidelines note that psychologists should “describe themselves and their activities and should avoid deceptive statements and inappropriate or excessive inducements.” While these guidelines are applicable to on- and offline research, there is heightened applicability in cyberspace whereby a website user might be conducting activity which they may realize is not quite “private” in a literal sense, but nonetheless neither is it an activity they want documented in a research publication. Mentioned earlier was privacy and confidentiality. A further concern noted by Binik et al. (1999, p. 86) is the inability to completely guarantee data security: “Promises of anonymity on the Internet can rarely, if ever, be given with 100% certainty, since a persistent hacker or an official with a court order may be able to discover the identity of research participants.” Hacking indeed remains a concern, however, given that most scholars today would use Internet-connected computers to store sensitive data collected in *offline* settings anyway, hacking is not uniquely or additionally pronounced for online research.

While obvious risks – reputational, emotional, and psychological – exist for participants in sex research, numerous risks also exist for researchers. Doing online sex research potentially exposes a researcher to illegal sexual activity and prohibited sexual images; situations which could place a scholar in a legal tangle and which are circumstances unique to online sex research.

3 Secondary Research: The Internet and Desk Research

Most research projects will begin with a desk research stage whereby readily available, on-topic material is assembled without fieldwork. Secondary research materials – work that has already been published such as books and reports and journal and newspaper articles – are reviewed to gauge what is already known about a topic, to ascertain what areas remain to be investigated and to determine whether fieldwork is necessary (see also ► Chap. 29, “Unobtrusive Methods”). If fieldwork remains desirable, the desk research stage helps brief a scholar about what research methods have used previously – both to positive and negative outcomes – in order to design suitably ethical projects and to expand a field of research. The Internet has completely revolutionized this process.

The *desk in desk research* was once used relatively loosely whereby this process could be executed at the scholar's own desk but also at desks and on surfaces in a range of libraries and archives. The Internet, however, has made *desk review* much more literal whereby the entirety of the desk review process can be conducted from one's own desk, in a fixed location, via utilization of an Internet connection. Doing so saves enormous amounts of time navigating through documents and commuting between libraries and other locations. Interned-aided desk research is also notably cost effective: not only is money saved on travel, but if the scholar is affiliated with an education institute, they will likely have access to full-text scholarly databases.

Aside from cost-saving and convenience, the Internet broadens the range of secondary materials available for analysis. On a cursory level, it means that a newspaper archive search can easily be conducted from one's own desk as opposed to sitting behind a microfiche machine in a library. Equally, the (not uncontroversial) Google Books library project has resulted in some 30 million books being scanned and (in varying degrees) made accessible to scholars no matter their location (Wu 2015). Amazon's "look inside" feature accomplishes something similar.

While the usefulness of the Internet in conducting a desk review is undeniable, it would be naïve to ignore that very worthwhile research projects that have transpired in its entirety without a single interview or survey being conducted. Tiefer (1991), for example, surveys a range of sexuality studies which use advertisements or cinema as a dataset; my own research is also heavily reliant on the analysis of popular media to tell the story of our relationship with sexuality. That said, it is necessary to acknowledge the limitations of desk research. Such problematizing is done not to devalue the importance of briefing oneself on the field, but simply to acknowledge that this stage does not exist without shortcomings.

Desk research in general and, more specifically in the context of sex research, is perceived as having some notable limitations; limitations which, incidentally, motivate many scholars to undertake *primary* research (as addressed later in this chapter). First, the very nature of desk research necessitates that only materials already in existence are explored. Such research is perceived not merely as frequently uninteresting, but as lacking in the innovation, newness and gravitas that new results would have. This is particularly important in the context of publication. Many journals prefer to publish new and seemingly innovative research as opposed to review articles without primary data. This frequently skews the research that scholars elect to produce. Marketing scholars Paul Hague et al. (2013, p. 41), in their book on research methods, identify a range of other shortcomings:

It may be that we are suspicious of the secondary sources because we had no involvement in their compilation. It may be that the data we are looking for are not in quite the form we require. It could be that we have not searched long enough or dug deep enough to see if this information is already available. Sometimes, desk research seems too easy. A big decision surely needs a lot of money spending on it and merits an original piece of research.

While Hague et al. were discussing desk reviews in the field of marketing, these concerns also plague sex research. Tiefer's acknowledgement of the criticism of, for

example, feminist analyzes of advertisements or films, is part of a bias toward “scientific” studies as opposed to secondary data analysis; the latter which might still teach us about society and the sexual mores and scripts produced within but which does not utilize primary data.

4 Primary Research: Online Materials

Autobiographies, memoirs, diaries, and correspondence are all part of the deluge of materials considered as primary sources. While, as discussed earlier, the Internet has made a range of materials – books and archives and articles, for example – accessible, the Internet itself has also been crucial in the *creation* of such material. People have, of course, been writing and publishing diaries and memoirs for centuries. Whereas the diaries that got studied historically were commonly documents written privately and studied or published posthumously – even if, as writer and literary critique Thomas Mallon (1984) speculated, many writers secretly imagined an audience for their musings – blogs take a different form. As described by media theorist Geert Lovink (2008, p. 6): “Blogs experiment with the public diary format, a term that expresses the productive contradiction between public and private in which bloggers find themselves.” Blogs are a very good illustration of Madge’s betwixt/ between categories as an example of writing online that is both simultaneously private and public (see also ► Chap. 77, “Blogs in Social Research”).

Blogging, a practice dating back to the earliest days of the Web, allows users to write and instantly publish entries. While the concept of a deliberately public diary raises concerns about performance and authenticity (Lomborg 2014; Whitehead 2015; van Nuenen 2016), the very same concerns also plague more traditional diaries (Mallon 1984), and as expanded on throughout this chapter, the idea of their only being one true self and one true expression is fraught (Rosewarne 2016d). Private diaries as well as more public ones like blogs provide a fascinating resource for scholars, particularly in relation to sex.

The writer and memoirist, Kerry Cohen (2013, p. 12), identifies that “[words] help us see who we are in our darkest, most private places. There are few memoirs this is truer for than sex memoirs, for nothing elicits vulnerability quite the way sex can.” Certainly for sex researchers, the sex memoir has served as useful research source material. While books like Frank Harris’s volumes *My Life and Loves* (1922–1927) or Ingeborg Day’s *Nine and a Half Weeks* (1978) have historically proven illuminating for scholars, the number of book-length sex memoirs pale in comparison to sex blogs, material predominantly produced by women (Attwood 2009) and which often produce a level of immediacy and explicitness absent from offline publications. While the veracity of sex blogs and whether considering them as akin to diaries are debates had elsewhere (Cardell 2014), the Internet nonetheless has facilitated the creation of a new source of primary source material where first-person sexual confessions are made available online, providing valuable individual testimonies, obtained without having to apply for permission from an ethics committee.

While sex blogs are a good example of a new source of public data available for analysis, they also provide insights into some very medium-specific ways of being sexual: from insight into netporn-aided sexual fantasy (Muise 2011) to the exhibitionist titillation that comes from public sexual confessions, of the caliber that only the Internet can so easily deliver (Wood 2008; Rosewarne 2011, 2014, 2016a; Fullwood et al. 2013).

This section has focused on the Internet's role in the creation of public diaries and thus the creation of new sources of data for investigations into human sexuality. Blogs, however, are not the only primary source research material available on the Internet. The study of the contents of sexual interactions in chatrooms (Koch et al. 2005) and in online games (Marteya et al. 2014), the presentation of the sexual self in dating profiles (Rosewarne 2016a, b), in vlogs (Biel and Gatica-Perez 2013), and in amateur porn (Paasonen 2010), and analysis into the sexual interactions between members of social network sites such as Fetlife (Fay et al. 2015), along with the activity logs of shopping sites (Coulson 2015), each provide new and notably *medium-specific* materials for scholars to mine for insights into human sexuality.

5 Primary Research: The Internet and Participant Recruitment

While the Internet has provided sex researchers vast quantities of new information, the technology has also had a major role in reconceptualizing a very traditional area of research: participant recruitment. Primary research is about the conjuring of new questions and the obtaining of new answers to research quandaries that either have not yet been posed, or – at the very least – not posed in the way that a scholar intends to. In order to undertake this kind of research, a constant supply of people willing to fill in surveys, answer questions, and sit in laboratories are needed. The Internet helps enormously in this regard. Psychologists Danielle Murray and Jeffrey Fisher (2002) summarized the range of reasons that the Internet has become so indispensable in soliciting research participation including that doing so is efficient and cost effective, that scholars are able to get samples up to four times larger than those organized in-person, and that much money is saved on paper and other stationery costs by relocating operations online. The Internet enables research participants to be found anywhere in the world and for a potentially larger sample of primary data to be collected. From Interviews using Skype (Deakin and Wakefield 2014) or questionnaires using Survey Monkey (Waclawski 2012; see also ► Chap. 76, “Web-Based Survey Methodology”), the Internet has meant that some of the traditional impediments to primary research such as recruitment time, costs, and geography are rendered less important. Scholars have also noted other advantages to online primary research such as physical distance from researchers encouraging participants to self-disclose in ways less likely to transpire in a face-to-face environment (White and Thomson 1995; Reid and Reid 2005). Such a method also helps a scholar to circumvent “gatekeeper” concerns (whereby access to participants in a particular organization or clinical setting needs to be granted to a researcher) (Coulson 2015).

Conducting research online also allows participants greater flexibility with the completion of, for example, surveys, enabling them to do so at a time, and in a place, convenient for them (Coulson 2015).

Using the Internet for participant recruitment boasts a range of obvious positives. Worth acknowledging, however, are some of the concerns; concerns which do not devalue the use of the technology in this regard, but nonetheless force deeper thought on research design.

Scholarly work on online methodologies frequently (although increasingly less so) spotlight limitations such as not everyone having a computer or Internet access, thus in essence excluding some likely already-marginalized people. While these factors of course are becoming decreasingly relevant in a world of smartphones, wifi, and public libraries with Internet access, they nonetheless remain relevant in countries where Internet use is not ubiquitous. Equally, early online research concerns, such as fears about those white, wealthier, educated men who once dominated Internet use and, in turn, datasets, have become dramatically less relevant 20 years on where online activity is near universal.

More pressing, however, are issues created by some of the benefits of the technology. In any research project, concerns are raised about representativeness and the degree to which the sample reflects the broader community. While the Internet facilitates the advertising of projects and the ability to locate and easily target individuals and communities, ultimately the sample still ends up being self-selected: these are individuals who have *volunteered* to participate. While the lack of representation in a self-selected sample will exist regardless of where participants are recruited and is not an Internet-specific problem, nonetheless, if the Internet is selected as the exclusive recruitment tool over other sampling methods such as *stratified random sampling* or *opportunity sampling* (Liamputtong 2013; Patton 2015), then this lack of representativeness may be more pronounced.

Mentioned earlier was the convenience factor of research participants being able to complete surveys or answer online questions whenever it is most convenient. A downside of this, however, is that the researcher has little control over the setting in which participation transpires, something problematized by criminologist Lynne Roberts (2007, p. 23): “This means [researchers] cannot tailor instructions to an appropriate level for an individual, clear up any misunderstandings (unless contacted by e-mail) or ensure the survey or measure is completed in an environment free from distractions.” A connected concern centers on response quality: studies indicate that written responses tend to be briefer and less comprehensive than verbal ones (Burton and Bruening 2003); thus without a researcher asking questions, follow-ups, explanations, and expanded answers are thwarted.

Noted earlier was the ability to engage in global recruitment of research participants. This, of course, creates its own challenges. In nursing scholars Eun-Ok Im and Wonshik Chee’s work (2004) on online methodologies, they discussed a range of projects where the Internet was used for recruitment. If documents, for example, are only made available in English, the ability to globally recruit means in practice that only people with relatively strong English skills can participate. Even then, mastery of English does not fully account for uses of, for example, idioms which

may seem unimportant in a survey design but may result in uninterpretable answers. Im and Chee (2004, p. 295) reflected on their study and identified: “Since data were collected using only English, the validity of foreign terms identified to be used in cancer pain descriptions from the nine countries may be threatened by language problems of the participants as well as the translation process.”

Another concern, and one specifically pertaining to ethics and sexuality, is anonymity. While anonymity online raises issues pertaining to identity and honesty, and while sometimes it may encourage participants who might be reluctant to expose their identity, there are some notable shortcomings. The capacity for online participants to create a false identity – in line with the identity play that the Internet is renowned for (Rosewarne 2016a, b) – means that factors frequently essential in data collection, like the gender of the participant, may not be accurately gleaned online.

Like any research method or sampling technique, using the Internet has a series of deficits. Such factors, however, have not diminished the desirability of using the technology, particularly given that doing so gives scholars not just a way to target a lot of possible participants efficiently and effectively, but enables specific kinds of participants to be targeted, something with pronounced relevance to sex research.

6 Primary Research: The Internet and Sexual Subculture Participant Recruitment

The Internet has completely revolutionized how individuals experience sexuality, in turn altering expressions of intimacy and becoming a key source of informal education (Rosewarne 2011, 2015, 2016a). Resultantly, the Internet has become a one-stop shop for sex researchers: there they can observe and collate, and as discussed, *recruit* research participants. Social researchers Wendy Bostwick and Amy Hequembourg (2013, p. 658), for example, discussed the use of the Internet in specifically targeting bisexuals, identifying that the technology “has opened up innumerable avenues to conduct targeted recruitment and research. Bisexual-specific listservs are not new, but the proliferation of social media venues (e.g., Facebook and Meetup groups) has made Internet recruitment of bisexual participants particularly appealing for both face-to-face studies and Internet-based survey research.” Highlighted here is the use of the technology to investigate populations notoriously difficult to target, in turn helping to create truly representative research samples. Psychologists Danielle Murray and Jeffrey Fisher (2002, p. 6) discuss some of the limitations of social science research which tends to rely on university undergraduate participants because “this population is an easy-to-access, convenient, and inexpensive group of participants. . . .” Such studies invariably exclude “hard-to-reach” subjects such as those who live in rural areas, who are not out, who are transgender or intersex, who eschew sexuality labels, who are sex workers, who have been trafficked or are any of these populations in association with other factors such as drug-use, homelessness, and mental illness (McDermott and Roen

2012; McCormack 2014; Bach and Dohy 2015; Barros et al. 2015). Murray and Fisher (2002, p. 7) propose that the Internet is an answer in accessing these populations: “Use of the Internet for data collection has already shown an increase in diversity over that of college student populations, and as computers become more accessible to the general public, the diversity of potential samples will increase dramatically.”

Use of the Internet in attracting research participants boasts a broad number of advantages in sex research. Firstly, while many reasons explain the “hard-to-reach” nature of certain minority sexual populations, a central reason for this is shame: these populations are hidden because there is a cost (real or perceived) to identity revelation (Rosewarne 2011). Participating in research online – with the ability to take advantage of anonymity and not having to engage in face-to-face contact – is considered one way to attract research participants who, otherwise, would not be inclined to participate and thus may not get their voices included in research projects (Liamputtong 2007, 2013).

While accessing hard-to-reach populations has been made substantially easier through use of the Internet, it is necessary to identify the shortcomings of using the technology in this regard. While on one hand, the Internet provides many ways to target groups, it should not be taken for granted that doing so is effortless. In psychologists Ilan Meyer and Patrick Wilson’s work (2009) on sampling in lesbian, gay, and bisexual populations, the authors spotlight that many websites, “particularly those that are sexually explicit or deal with provocative subject matters,” actually *prohibit* online solicitation of study respondents. On Fetlife, for example, it is very common for profiles to include a statement objecting to the information posted being used in research projects. Meyer and Wilson similarly identify that while advertising for research participants online might get an advertisement seen by many people, there is little correlation between the number of eyes on an ad and the number of respondents.

Another hard-to-reach population for the purposes of sex research is children, something that Binik et al. (1999, p. 84) address:

In the past, researchers did not have easy or direct access to minors or patients independent of their parents, caretakers, schools, or some third party or institution. This insured that legal third parties were at least minimally aware of the research and were involved in giving consent. Now, many thousands of users under the age of 12 and legally defined as children use the Internet every day. . . . Potentially important research with minors (e.g., relating to surviving sexual abuse or childhood sexuality practices) might be effectively carried out over the Internet, possibly even more effectively than face-to-face interviewing. . . .

While the ethics pertaining to conducting research with children – specifically around issues of sexuality – is addressed elsewhere (Flanagan 2012; Sparrman 2014), as outlined by Binik et al., the Internet creates both a motivation to undertake research with children – as a result of things such as access and their exposure to erotic content – but also creates the capacity to reach children in ways outside of traditional education settings often blocked by gatekeepers.

7 Primary Research: Online Ethnography

An interesting hybrid between primary and secondary is online ethnography whereby fieldwork gets undertaken from the comfort of a desk. Discussed earlier was the capacity for an enormous amount of research to be conducted from one's own desk. While commonly desk work is associated with secondary source data collection, the Internet has also revolutionized how *primary* research is conducted.

Thinking of the Internet as a place is well established (Rosewarne 2016a, b, c). Thinking of it as a somewhere that people can go, or be from, underpins popular perceptions of it as a badlands or Wild West at one end of the spectrum and as a new frontier at the other. As related to fieldwork, the idea of the Internet as its own geographic site(s) creates the capacity for a scholar – without leaving their desk – to observe social interactions; a research method known as *virtual ethnography* (Hine 2008). In practice, online ethnographies have been conducted on communities as diverse as Brazilian migrants (Schrooten 2012) to software developers (Cordoba-Pachon and Loureiro-Koechlin 2015), but for the purposes of my chapter, it is ethnographies in the realm of sexual communities that make this research method particularly useful. Discussed earlier was the Internet offering the capacity to analyze a range of online activities such as blog posts, chatroom interactions, and amateur pornography. In fact, the virtual possibilities for ethnography are much broader, as outlined by Binik et al. (1999, p. 82):

The growth and popularity of personal Internet services allow for novel investigations of sexuality at home, in the absence of physical presence, and under conditions of relative anonymity. By making use of existing or experimental on-line sex therapists and sexual self-help or entertainment groups, researchers can study topics such as interpersonal attraction, flirting, sexual language, sexual self-help, sexual writing, role playing, and therapeutic relationships.

Such ethnographies have been conducted widely in the study of sex. Social researcher Faracy Grouse (2012), for example, conducted an ethnography of the sexual behaviors of Second Life players using an avatar to investigate how intimacy gets transformed without physical contact. Criminal justice scholars Kristie Blevins and Thomas Halt (2009) used similar techniques to study the attitudes of male clients of sex workers as exhibited in Web forums. Sociologist Joy Hightower (2015) conducted a virtual ethnography which observed the interactions of women on a lesbian dating website to examine gendered bodily presentation, label use, and peer perceptions.

Just as the Internet has dramatically benefited the desk review stage of research, it has also overhauled ethnography (see also ► Chap. 26, “Ethnographic Method”). While many scholars will, of course, still want to undertake in-person observations in places like gay bars (Johnson 2005), pride marches (Ammaturo 2016), and swingers conventions (Kimberly 2016), the Internet opens up scope for conducting this kind of research without leaving one's desk. This can make work substantially cheaper, more convenient, and able to overcome geographic boundaries, but it also taps into a reality that the Internet does not just create new ways and places to study

sex, but rather the technology has completely overhauled the way sex itself is experienced and thus, in turn, generates its own, medium-specific data. In my book *Intimacy on the Internet: Media Representations of Online Connections* (Rosewarne 2016a), I examined the range of ways that the Internet has revolutionized the experience of sexuality, from changing how we meet partners, maintain relationships, self-stimulate, fantasize and obsess, have “sex,” hook up, cheat and betray, experience our interests vicariously, dabble in subversive sexual practices, expand our networks, and how we feel less alone. In each of these areas, the Internet plays a crucial role and one that necessitates research methods that observe these practices in situ. Virtual ethnography is one method that facilitates this. This technique also has advantages of being less intrusive than interviews, focus groups, or physical observations and it can be viewed as (comparatively) more authentic than had the researcher orchestrated a space for interactions to transpire.

Like each of the methods discussed in this chapter, virtual ethnography is not without criticism. Scholars have problematized this method as so fundamentally dissimilar to traditional fieldwork that it is inappropriate to dub it as such (Lenihan and Kelly-Holmes 2016). An extension of this is that by just observing, for example, a lesbian’s interactions in a dating website, does not provide data on her life in its entirety (although, arguably, even offline methodologies would struggle with gleaning such information). Limitations similarly exist in extrapolating data from sexual spaces online and assuming that this provides insight into offline activity, although again, it is hard to imagine that any methodology could truly encapsulate every aspect of identity. Worth noting, the same concerns about authenticity that plague other digital research methods plague ethnography. Communication is somewhat compromised if visual cues cannot be monitored. Similarly, ethical concerns exist about researchers “lurking without consent” (Roller and Lavrakas 2015, p. 190). While these limitations should not be considered as deal breakers – consent can be obtained and a broader definition of “authenticity” can be utilized (Rosewarne 2015, 2016b) – nonetheless it is worth identifying that this method does have unique elements that need to be accounted for.

8 The Internet and Deceptive Responses

In this section, the role of the Internet in obtaining more deceptive data, and alternatively *more truthful* data is examined. While deception is a possibility in any human research, this concern is more pronounced in the context of work done online. Since its inception, the Internet has been framed as a kind of badlands (Rosewarne 2016a, b). A key underpinning of this perception is the capacity for the concealment of identity and, in turn, the concealment of potentially duplicitous intent. While this can partly be explained by techno- and cyberphobia whereby things that are new are both feared and perceived as malevolent (Rosewarne 2016c), the reality is that some people *are* frequently deceptive online. The ability to conceal identity, to play with identity, to don the guise of another gender, and to exaggerate appearance are all behaviors fostered by the default-anonymity of the Internet and

what have come to be construed as one the many gameplay-like behaviors executed online; something legal scholar Chris Ashford (2009, p. 298) discusses:

These sites enable the formation of a “virtual identity” which may be regarded as “false”. . . This is particularly relevant in the construction of age. This may take the form of a 40-something male becoming a 30-something for the purposes of a networking site, or may attract the attention of the law where this is seen as representing a “subversive” motive, for instance in the “grooming of children.”

The possibility of this kind of deception has indeed long haunted online research. Sociologist Christine Hine (2008, p. 263), for example, discussed the issue of duplicity in her discussion on virtual ethnography:

Online ethnography, and indeed all research using data collected online, has been dogged by the question of authenticity. . . Such was the association between the Internet and identity play in the early days that considerable doubt was expressed whether enough trust could be placed in what people said online for their words to constitute grounds for any sound conclusions to be drawn.

While the capacity for deception must be factored into research design, this should be considered as less an impediment and more so as a complicating factor, and one that ultimately can yield fascinating findings in new areas. Ashford (2009, p. 302), for example, discusses the complexity of researching online sexual identities and the expanded scope created for unique kinds of analysis:

The Internet enables the identity of the researcher to be recast as a fluid, relentlessly shifting construct. Those researchers who maintain Facebook and other Web 2.0 accounts, project one self; another self may be projected on a dating or hook-up site, another in the classroom and a further self at a conference presentation. No single self can, or should, be regarded as ‘true’ in any absolute sense.

Outside of identity play, it is worth noting other kinds of deception transpiring as a result of the anonymity fostered by the Internet. The social scientist Ian Greener (2011, p. 52), for example, spotlights that the ability to be anonymous creates the capacity to be deceptive without consequence:

People taking part in research can behave in remarkably dishonest ways when the assurance of anonymity is in place. Research participants have been shown to be more likely to steal and to lie about test results they have taken, for example, when they believe they are anonymous.

While this might be interesting if a research project is about deception, it is often perceived as less helpful if scholars are seeking personal insight. While scholars have put efforts into refining techniques to validate identity and to verify things like age and signature, the reality is that truth and identity are concepts needing to be reconceived in the design of research projects using online methodologies.

9 The Internet and Truthful Responses

At the same time that we have questioned the truth of online responses and the *real* of online identities, there has been another set of conversations transpiring about the Internet's capacity to aid *greater honesty*: that anonymity can facilitate truth-telling because a person is not self-censoring in fear of judgment; i.e., serving as an online illustration of Oscar Wilde's famous "Give a man a mask and he'll tell you the truth." As applied to social research, Greener (2011, pp. 51–52) also sees capacity for positives to come from anonymity: "Offering anonymity will lead to respondents being more honest, and feeling that they can say what they believe without being concerned whether their answers will in some way be used against them."

Numerous scholars have spotlighted a capacity for heightened self-revelation online. Social researcher Mark Griffiths (2010, p. 9), for example, discusses the disinhibiting effects that have contributed to this: "For populations discussing sensitivities issues like addiction, this may lead to increased levels of honesty and therefore higher validity in the case of self-report." In the context of sex research, disinhibition can lead to heightened self-revelation of a caliber that sometimes struggles to emerge in offline research environments.

While as noted earlier, the identity concealing or identity fabricating possibilities of the Internet need to be acknowledged, so too do the very reasons why researchers have so enthusiastically embraced online spaces: research participants sometimes open up and self-disclose in ways that offline environments might never permit.

10 Conclusion and Future Directions

The Internet has completely revolutionized every aspect of sex: from overhauling our fantasies, supplementing our masturbation, helping us connect, hook-up, cheat, rinse, and repeat. It is no surprise, therefore, that with all these changes transpiring online, that the interest of scholars would be piqued. Scholars have delved into every aspect of sex online, probing the how, the where, and the why and putting under the microscope each element of this new private life accoutrement. Of course, for scholars, the role of the Internet in sex research is much more than just a new set of stuff to study. As discussed throughout this chapter, the Internet is *itself* something to study, but it is also a tool to explore sexual behavior occurring online as well as offline: research on online dating sites and hookup apps invariably involves online-instigated activity that often ends up playing out in real life.

While the Internet serves researchers as a tool and a source of data, it is important to recognize the complexity of this. Going online to do research creates an enormous array of benefits but also a range of methodological shortcomings and ethical concerns. Such factors do not devalue online research, but nonetheless create pause for thought for scholars and a necessity to think very carefully about research design.

A key challenge for researchers going forward – and, notably, a key issue for university ethics committees – is keeping abreast of new online tools that aid with

recruiting participants and also yield new materials of the kind sex researchers might be keen to study. In my experience, for example, students were navigating the use of Tweets and Facebook posts in research long before ethics committees settled on best practice as related to such material. Just as governments are challenged with needing to write legislation that meets constant technological change, scholars are charged with the same burden in regard to ensuring the ethics of their online methodologies.

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Emotion and Sensitive Research

123

Virginia Dickson-Swift

Contents

1	Introduction	2146
2	Research Work as “Emotion Work”	2146
3	The Research Process	2148
3.1	Ethics	2148
3.2	Data Collection	2149
3.3	Data Analysis	2150
4	Issues for Other Research Team Members	2151
4.1	Transcriptionists	2151
4.2	Research Assistants	2152
5	Working with Secondary Data	2153
6	Sources of Researcher Support	2154
6.1	Informal Support	2154
6.2	Protocols and Guidelines	2155
6.3	Guidelines for Transcriptionists	2157
7	Conclusion and Future Directions	2158
	References	2159

Abstract

Qualitative research on sensitive topics is often an emotional journey, not only for the participants but for others that may be involved along the way. It is now more than 20 years since Raymond Lee authored the seminal works *Doing Research on Sensitive Topics*, *Researching Sensitive Topics*, and *Dangerous Fieldwork* that raised the awareness of the challenges that researchers can face. More recently, Lee and Lee (2012) warned that the emotional challenges that researchers face when doing fieldwork are now difficult to ignore. Given this warning and the

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2145

growing numbers of reports from researchers, both empirically and in reflective accounts, an examination of the issues is timely for both novice and experienced researchers. Drawing on earlier empirical work with researchers in Australia (Dickson-Swift 2005) and published accounts, this chapter provides an overview of the emotional challenges inherent in this type of research. Suggestions for researchers, research supervisors, and others involved in the research team are presented. These can be adopted by academic or research institutions to ensure that researchers have the necessary support to carry out this important research.

Keywords

Sensitive research · Qualitative · Emotions · Emotional labor · Ethics · Training

1 Introduction

Undertaking qualitative research is often an emotional journey, not only for the participants but for others that may be involved along the way. There is growing evidence that researchers, research supervisors, transcriptionists, and research assistants face a number of emotional challenges while participating in qualitative research, particularly when that research focuses on sensitive topics and/or vulnerable populations (see Liamputtong 2007). Interest in the issues researchers face when researching sensitive topics is not new. More than 20 years ago, Ray Lee and Claire Renzetti authored a number of seminal texts outlining some of the key challenges researchers may face (see for example Lee and Renzetti 1993; Lee 1995; Renzetti and Lee 1993). The focus of their work was on both physical and emotional risks for researchers and participants across the spectrum of research methods. More recently, Lee and Lee (2012) warned that the emotional challenges researchers face when doing fieldwork cannot be ignored. Given this warning, and the growing numbers of empirical and reflective reports from researchers, an examination and consideration of the issues researchers face is timely. While much of the information in this chapter is drawn from accounts from qualitative projects, the key messages are also applicable to those researchers working on quantitative or mixed method studies. In this chapter, I draw on my earlier empirical work with researchers in Australia (Dickson-Swift et al. 2005) and a range of published accounts from across the globe, drawn from a range of disciplines to provide an overview of the emotional challenges faced by researchers. I provide some suggestions for researchers, research supervisors, and others involved in the research team. These can be adopted by academic or research institutions to ensure that researchers have the necessary support they may need.

2 Research Work as “Emotion Work”

Emotion work theory can provide a framework for understanding researchers’ experiences throughout the research process. The concept of “emotion work” was initially developed by Arlie Hochschild in her now classic study *The Managed Heart* (1983),

which explored the experiences of flight attendants and how they managed their emotions on a day-to-day basis on the job. The terms “emotional labor” and “emotion work” are often used interchangeably in the literature. Initially, these two concepts were developed by Hochschild (1983) to mean different things. “Emotional labor” was used to refer to emotional management during work done for a wage, and “emotion work” was used to refer to the work involved with dealing with other people’s emotions (James 1989). In her definition of emotion work, Hochschild (1983, p. 7) states that it is “management of feeling to create a publically observable facial and bodily display whereby people work on managing their own and the other people’s feelings to comply with a set of ‘feeling rules’” that direct the type, intensity, and duration of the emotion (Stets and Turner 2014). The concept of emotion work and the resultant consequences of undertaking it have been documented in a range of occupations including airline staff (Hochschild 1983), front line service (including retail assistants (Van Maanen 1990; Ashforth and Humphrey 1993; Grandey et al. 2012), nurses and caring staff (Pisaniello et al. 2012; Bailey et al. 2015; Lovatt et al. 2015), physicians (Larson and Yao 2005), beauty therapists (Sharma and Black 2001), call center staff (Mulholland 2002), teachers (including academics) (Bellas 1999; Ogbonna and Harris 2004; Isenbarger and Zembylas 2006), barristers and legal staff (Harris 2002; Anleu and Mack 2005), clergy (Grauel 2002; Cotton et al. 2003), and sex workers (Sanders 2004), models (Mears and Finlay 2005). While there is not yet an extensive body of work focusing on emotion work done by researchers, interest in the other members of research teams in this area is growing (see for example, Campbell 2002; Dickson-Swift et al. 2009; Carroll 2013; Fitzpatrick and Olson 2015).

For the purposes of this chapter, I use the phrase emotion work when referring to any effort made by those participating in research (participants, researchers, or other members of the research team) to manage emotion and emotional displays. In relation to research, emotion work can take the form of what has been termed “surface acting” and “deep acting” (refer to Goffman 1959 for an in-depth discussion of these concepts). Surface acting takes place when individuals manage the observable emotional expressions by controlling verbal or facial expressions (e.g., holding in tears) as well as other gestures and/or bodily displays (e.g., altering facial expressions) (Hochschild 1979, 1983). Deep acting, on the other hand, is thought to be a more complex activity requiring utilization of the techniques of cognitive emotion work. This can include attempting to alter the emotion by changing the thoughts associated with that emotion. For example, bodily emotion work includes attempts to change bodily processes to alter the emotional responses and expressive emotion work includes altering outward expressions to shape underlying emotions (Hochschild 1983). More recently, authors interested in emotion work in research have also utilized the concept of “habitus” to explain and extend the theory to include the unconscious, embodied, and habitual aspects of emotion work (Fitzpatrick and Olson 2015).

While not all research into researcher emotions uses the concept of emotion work to describe the work undertaken, there is a growing body of research that refers directly to researcher emotion. Examples from the UK and Europe (Bloor et al. 2007, 2010; Mitchell and Irvine 2008; Parker and O’Reilly 2013; Benoot and Bilsen 2015), USA and Canada (Campbell 2002; Carroll 2013), and Australia and New Zealand (McCosker et al. 2001; Dickson-Swift et al. 2009; Johnson 2009; Bahn 2012; Bowtell

et al. 2013; McKenzie et al. 2016) provide both empirical and reflective accounts across a wide range of health and social science disciplines (including health, sports psychology, urban studies, geography, marketing, and occupational research). While this list is not exhaustive, it is illustrative of the breadth and depth of the documented accounts of the emotional challenges researchers might face.

3 The Research Process

In this section, I draw a range of published material to outline some key challenges documented by researchers throughout the research process. These will be provided in sections relating to ethics and risk, data collection, and data analysis and include some discussion of the impacts on transcriptionists and research assistants.

3.1 Ethics

Ethics guidelines are primarily focused on nonmaleficence and beneficence with regard to research participants which is the principal focus of ethical review (see also ► Chap. 106, “Ethics and Research with Indigenous Peoples”). As part of the review process, committee members consider emotional and physical risks to research participants and ensure that a number of strategies are in place to mitigate any harm (National Health & Medical Research Council 2007; Social Research Association 2006). Researchers completing ethics applications are well versed in the need to protect participants from physical harm but are not required to systematically consider any emotional harms that they may be exposed to. In her reflections on a 6-year social research project focused on a community street soccer program, Emma Sherry (2013, p. 280) shares her experiences:

Each aspect of the paperwork required significant levels of detail and thought, to ensure no harm was done to my vulnerable research participants. But what was missing was a section that led me to consider any potential harm to myself as the researcher, let alone an opportunity to debrief.

Institutional review boards (IRBs) are well versed in protecting participants, but the protection of researchers is often not considered in deliberations (Dickson-Swift et al. 2005). Many of the existing safety protocols designed to protect researchers focus narrowly on physical risk which are often considered part of an organizational duty of care under Occupational Health and Safety legislation (Noblet 2003; Social Research Association 2006; National Health & Medical Research Council 2007; Kennedy et al. 2012). Ethics committees and IRBs have procedures and policies in place to manage physical risks to researchers when undertaking fieldwork; however, guidelines and policies for managing and mitigating emotional are still largely absent. Frustration and lack of preparedness for the emotionality of some fieldwork encounters are not uncommon;

Nothing that I read in planning this study prepared me for the emotionality of the research process. I read recommendations about how I should address confidentiality, harm, deception and privacy, but there was not much written on such things as the impact on the researcher of listening to people talk about their grief, their fears and anxieties, sometimes being expressed for the first time and times of crisis. (Rowling 1999, p. 175)

Susanne Bahn's (2012) paper outlining the issues in relation to risks in fieldwork highlights that risk reduction policies for researchers often fail as they mostly rely on Heads of School/Department, PhD supervisors, or Chief Investigators to decide on the level of risk. Since early 2000, there have been a number of publications relating to risk in research questioning whose responsibility it is to ensure that researchers are safe in the field (see for example, Kenyon and Hawker 2000; Johnson and Clarke 2003; Dickson-Swift et al. 2005; Bloor et al. 2007).

In a study focused on researcher safety, Kenyon and Hawker (2000) set up an online discussion board which attracted 46 participants from the UK, Australia, USA, Finland, Norway, Sweden, Italy, and Canada. Only one of the 46 participants had ever been issued with a safety code of practice that outlined key issues for researchers and how to handle them. Similarly, in an Australian study completed in 2005, Dickson-Swift and colleagues investigated 37 university ethics application forms to determine the number that addressed the safety of the researcher. They found that in 78% of cases, there was no reference to researcher safety across the domains of physical, emotional, and psychological safety (Dickson-Swift et al. 2005). While there has been no follow-up work in this area within the Australian context, there has been some similar research undertaken in the UK. In 2007 Bloor and colleagues undertook a Commissioned Inquiry into the Risk to Wellbeing of Researchers in Qualitative Research (Bloor et al. 2007) conducted by Qualiti (Qualitative Research in the Social Sciences: Innovation, Integration and Impact; a node of the Economic and Social Research Centre's National Centre for Research Methods). As a follow up to this study 83 PhD students were invited to post their stories onto a website and then 13 participated in an in-depth interview to elaborate on the practices in place to protect researchers in the field (Bloor et al. 2010). The recommendations from the inquiry, the study report and subsequent publication included providing safety in the curricula, health and safety audits for all university departments, and specific questions in ethics applications that addressed contextual safety issues (Bloor et al. 2010, p. 52).

While we have not seen the widespread adoption of this approach to identifying and managing risk for researchers, a number of guidelines have been suggested which will be presented later in this chapter.

3.2 Data Collection

Researchers have provided many accounts of emotionally charged situations during data collection. Rebecca Olson (Fitzpatrick and Olson 2015, p. 51) reflects on her own experiences of research with caregivers to explore their responses to a cancer diagnosis of a spouse;

At times, I felt sadness and frustration in response to his stories, but I didn't cry. I was aware of my facial expressions and actively tried to sustain an "open" and "active listening" expression: lips closed, gaze fixed on either Joe or my tea cup. I left the interview feeling tired but indebted to Joe for his honesty. Several days later, while watching television with a group of friends, as a character learned his father was dying from cancer, I felt the sadness of Joe's and other interviewees' stories and cried for half an hour.

Similarly, Rebecca Campbell (2002, p. 6) shares her reflections on interviewing rape victims,

As I listened to her preface her story with the information about her rape I realized this was something more than just a research interview. I was not just the project director, not just a researcher, I was the first person she was going to tell to trust with this information. I was being given something very fragile, and yet very strong. It was a sobering responsibility. We both knew what was coming was going to be hard for both of us.

There are also many accounts of researchers reporting physical and sometimes emotional exhaustion from undertaking interviews. Considering the nature of the interviews, this is not surprising.

...by the time I got home I was just like exhausted, just emotionally exhausted. I was just interviewing all day, I would have done more than five interviews – I was just interviewing all day, by myself and I was really buggered, yeah I was had it. I found it really emotionally draining ... it got to the point where I had to allocate time ... I can go and do the interview in the morning but then I will have to block out the rest of the day because after that I need to go home and I need to digest what has happened ... go through it in my head. (Dickson-Swift et al. 2009, p. 71)

Researchers also highlight that it is often difficult not to get drawn into the emotion, especially when face-to-face with another person who is experiencing emotion (Dickson-Swift et al. 2009; Jafari et al. 2013). Some researchers do not attempt to hold back or manage their emotions during the interview process, instead preferring to become part of the experience themselves. Dickson-Swift et al. (2009, p. 64) reported occasions where researchers were emotionally overwhelmed during the research, stating that this was often directly attributable to the participants becoming emotional.

I cried pretty much the whole way through it because once she got upset it was impossible not to be upset you know... seven no its eight – eight out of ten people I interview cry and they cry sometimes uncontrollably, it's a very sad thing to talk about ... and how can you, as a person not get caught up in those feelings of sadness. (Dickson-Swift et al. 2009, p. 64)

3.3 Data Analysis

It is important to recognize that the emotional impact can extend well beyond the data collection phase as the researcher moves into data analysis and writing up of the findings. The effects on the researcher can be cumulative, resulting in emotional

exhaustion (Woodby et al. 2011). Data analysis often becomes a time for reflection on emotions for researchers,

The complex emotions I experienced while collecting the data were relived and recounted through the passing months and years when I conducted manual data analysis. On reflection, I realise that during both the data collection and analysis phases, I engaged in an amount of emotional management. Storing away sadness and fear during the exhilarating fieldwork phase only to be unexpectedly revisited by it during the long and lonely phases of data analysis. (Jafari et al. 2013, p. 1189)

Based on a qualitative study focusing on elder neglect, Band-Winterstein et al. (2014, p. 536) reflect on some of the challenges related to the emotion connections that became evident during the analysis process.

They “got to me”, I was touched, they managed to break through my walls. At first, I tried to keep my distance and let the person talk. After some time, I found myself shamelessly asking questions about their personal lives. And I felt that I was connecting with them. They had waited for me, which was very touching and I don’t know how to explain it, only that “I am taking them with me.”

Charlotte Benoot (Benoot and Bilsen 2015, p. 5), a novice researcher undertaking interviews with people caring for cancer patients, reflects on her feelings in the coding and analysis phase of the research.

The act of coding and transcribing made me relive the emotions I suppressed while conducting an interview, without the necessity of controlling them. This was because I was alone at that time, which gave me more freedom to express my feelings, and also because I had had more time to take the story in. Moreover, the repeated listening, replaying, and typing intensified the emotional responses to sensitive materials.

4 Issues for Other Research Team Members

In addition to considering ethics and risk to the researcher, there has been an increase in acknowledgment of the possibility of physical and/or psychological harm being extended beyond participants to include transcriptionists and research assistants and those working with secondary data.

4.1 Transcriptionists

While there are many documented examples of emotional risks and emotion management for researchers, transcriptionists working with data from interviews, particularly on sensitive topics, are often left out. There is now evidence that listening to audio recordings and transforming those audios for analysis the potential to have an emotional impact on the transcriptionist (Gilbert 2001; McCosker et al. 2001;

Darlington and Scott 2002; Gair 2002; Warr 2004; Lalor et al. 2006; Etherington 2007; Sherry 2013; Kiyimba and O'Reilly 2015). Often considered a clerical role, the act of transcription can impact on those that undertake it.

It is definitely important to know what you are getting into, not to think of it as a typing job, think of it, um, as something that will have repercussions that you will wake up in the night and think about it on a level that you just wouldn't expect from that sort of, that level of clerical work really (Kiyimba and O'Reilly 2015, p. 102).

People who undertake transcription of interview data are one of the few people (besides the researcher) to hear the actual voices and expressions of emotion of those people participating in the interview (Kiyimba and O'Reilly 2015). Concern for those that undertake transcription work has been documented for almost 20 years with Gregory et al. (1997) and McCosker et al. (2001) examining the role of the transcriber as a vulnerable person. A transcriptionist must listen and re-listen to the data to undertake the process of capturing the spoken word which can result in the data becoming embedded within their consciousness. They are often not considered in the ethics process except for the signing of a confidentiality agreement. This poses a problem when the data refer to disturbing events or traumatic life experiences (Gregory et al. 1997). There are a number of accounts of transcriptionists becoming emotional when listening to the data (Gregory et al. 1997; McCosker et al. 2001; Wilkes et al. 2014; Kiyimba and O'Reilly 2016). One recent example draws on research with 12 transcriptionists in Australia and New Zealand (Wilkes et al. 2014). Some transcriptionists reported finding the process of transcription overwhelming resulting in them deciding not to take on any more work related to some research projects. Participants also highlighted that they faced a number of challenges during the process including negative emotional effects (e.g., anger and sadness) and negative physical effects (sleeplessness, vomiting, headaches, and stress) and that they used a number of personal strategies to manage these effects (including debriefing, support from family and friends, and taking time out).

Evidence has shown that there is emotional risk for transcriptionists which are heightened if opportunities are not provided for support that includes debriefing and training including opportunities to talk about the emotional impacts of the work that they do (Etherington 2007; Kiyimba and O'Reilly 2015). A recent study undertaken across the UK involving 9 transcriptionists showed that emotional distress was perceived as a threat to the emotional welfare of those involved (Kiyimba and O'Reilly 2015). In some studies, the process of transcription has been considered as a form of emotion work which has may lead to burnout (Hochschild 1983; Dickson-Swift et al. 2009; Kiyimba and O'Reilly 2015). In order to ameliorate the risks to transcriptionists, they also need to be provided with practical and emotional support throughout the research process.

4.2 Research Assistants

While there are some considerations for researchers and issues for transcriptionists are gaining more attention, research assistants are another group that potentially face

emotional challenges related to the work that they do (Bahn and Weatherill 2012; Benoot and Bilsen 2015; Mckenzie et al. 2016).

I knew we had something set up for the participants. But suddenly I wondered if we had it set up for the research assistants. If I carried this story home in my head for a couple of days, what might be the impact on a more junior team member? I must make a point of meeting up with <> for a chat. It will be useful for me too. Self awareness can be such a draining thing, ha, ha? (Bahn and Weatherill 2012, p. 8)

Many researchers report reaching a point of emotional saturation from undertaking emotion work (Sherry 2013). This sense of emotional saturation was also reported in the study by Dickson-Swift et al. (2009, p.72).

... it's not just about saturation of when you don't get new themes...it's about your saturation as well – how much you can actually take and I could not, could nothave fronted for another one of those interviews.

Emotional saturation may be accompanied by feelings of exhaustion, burnout, guilt, tiredness, sleeping difficulties, anxiety, and gastrointestinal upsets (Dickson-Swift et al. 2009; Benoot and Bilsen 2015). In the study by Benoot and Bilsen (2015) Charlotte Benoot reflects on her own experiences in undertaking research with cancer patients that lived alone:

As a consequence, I started to internalize the bodily complaints my patients had, which means that I often literally could feel the pain symptoms or nausea from the patient I was interviewing at that time. Another consequence was that the fear of getting cancer myself grew with every interview I took (Benoot and Bilsen 2015, p. 5).

5 Working with Secondary Data

Social research utilizing secondary data is growing in popularity in health and social sciences. There is increasing acknowledgment that undertaking this type of research may also pose emotional risks to those undertaking it (Moran-Ellis 1996; Fincham et al. 2008; see also ► Chap. 119, “Feminist Dilemmas in Researching Women’s Violence: Issues of Allegiance, Representation, Ambivalence, and Compromise”). Secondary data in this context refer to data that have been assembled by another person rather than data collected originally by a researcher. Data sources for this type of research are often documentary but could also include a range of other types (e.g., digital, visual, or aural) (Fincham et al. 2008). Fincham and colleagues undertook a study focusing on the review of coronial files of people who had suicided. Their research highlighted that the contents of such files can have a profound emotional impact on those who review them and that researchers undertaking this type of work need to consider their own self-care and have a range of support systems in place to ameliorate any risks to researchers or other members of the team. In an earlier

study, Moran Ellis (1997) refers to the possibility of emotional risk for researchers as feeling “pain by proxy” providing examples from a study on child sexual abuse. She reports,

I felt appalled by what I was finding out, and I felt much pain by proxy for the children who had been subjected to what amounts to physical as well as emotional and sexual assault. I could barely contemplate the pain they had felt. ...And yet I found I couldn't not think about it. (Moran-Ellis 1996, p. 181)

6 Sources of Researcher Support

In the following section, I outline some of the supports that may be useful for researchers.

6.1 Informal Support

A number of researchers have reported using informal support networks of colleagues, trusted friends, and family members for support and debriefing throughout the research (Hubbard et al. 2001; Dickson-Swift et al. 2009; Fahie 2014). This informal peer support is very important for researchers particularly as the much of the discussion about emotions in research and how the researcher actually “feels” in the process is often done informally at the photocopier, coffee machine, or in the corridors (Dickson-Swift et al. 2009). In a study exploring researcher trauma for researchers working on sexual violence research, Jan Coles et al. (2014, p. 106) reported a number of instances of how informal support was used.

At the time, I did not realize how vitally important it was to protect myself. The organization I worked for did not provide an embedded support system for its staff. Our support came from each other as colleagues and friends, and to an extent, this enabled me to survive mentally, but it did not help me eradicate the root causes. I became adept at burying the emotional stress but, of course, it continues to surface in a number of guises.

Mick Bloor et al. (2007, p. 34) sum up the problems associated with a reliance on using informal networks for this type of support,

Whilst it is inevitable to a certain extent that there will be off-loading at home, the formal exploitation of informal networks – for example, building them into research designs – is not deemed appropriate, and such strategies do not absolve research funders and institutions of their responsibilities to researchers.

While it is clear that undertaking qualitative research can be emotionally challenging for many researchers, it is important to note that some disciplines may better prepare researchers to deal with the emotional challenges through their postgraduate

programs. But this may not be the case for all researchers (novice or otherwise). Most postgraduate students have access to regular supervision within the university setting from their immediate supervisors. However, other more experienced researchers attached to universities or large research centers may not necessarily have access to regular formalized supervision (Campbell 2002; Carroll 2013). If we are to truly create a space for researchers to explore the emotional nature of the work that they do, then we need to ensure that appropriate support is offered, both institutionally and individually for researchers to do that (Benoot and Bilsen 2015).

6.2 Protocols and Guidelines

Most university and research organizations pay attention to the issue of physical safety for researchers, and there are risk management policies and protocols designed to mitigate any harm. Physical risks tend to be more easily recognizable (Paterson et al. 1999; Bowtell et al. 2013), and recommendations to ameliorate these types of risk include identifying possible threats and developing written safety protocols, not volunteering personal information and avoiding interviews in private homes (among other things). Sampson et al. (2008) determined that researchers actually perceive emotional harm as more prevalent in the field than physical harm. This highlights that the development and implementation of emotional safety guidelines for all members of the research team are just as important as the well-used physical safety protocols. However, emotional safety does not receive the same recognition within research guidelines leaving many researchers vulnerable to emotional harms. Almost 20 years ago, Martin Schwartz (1997, p. x) pointed out some of the emotional challenges faced by researchers:

Most academic research programs can provide advice on when logistic regression is a better tool than discriminate function analysis, but few have mentors who can talk about how to handle your uncontrollable tears late at night after a day of conducting interviews with victimized women.

Despite the many calls to introduce standardized protocols to protect researchers and research team members from emotional harm, it appears that few institutions and research centers have formalized them to date (Bloor et al. 2007; Dickson-Swift et al. 2008; Kiyimba and O'Reilly 2016). Questions have been raised about whose responsibility it would be to ensure that any protocols are implemented. Arguably, the safety (both emotional and physical) is as much a responsibility of ethics committees as participants (Dickson-Swift et al. 2008; Bowtell et al. 2013). Researchers have been encouraged to consider the ethical mantra of “do no harm” in relation to themselves as well as their research participants (Lee-Treweek and Linkogle 2000).

In the absence of any standard formalized recommendations, researchers have outlined their own approaches to emotional and physical risk management. Declan Fahie (2014), a social researcher from the UK, recommends the following personal safety tips for researchers (see Box 1).

Box 1 Personal Safety Tips for Researchers

- Undertake a risk assessment as part of the design
- Do not disclose personal details (home address or phone numbers)
- Ensure that your interviews are carried out in public places as much as possible (libraries, public meeting rooms, community houses, etc.)
- Inform your supervisor of your location and carry a mobile device and SMS when you arrive and leave
- Get a dedicated SIM card or voice mail box just for the research (these can be destroyed later)
- Monitor carefully the interview to assess the emotional impact and response of the interviewee
- Monitor your own response and have a plan for debriefing
- Make sure you have regular sessions with your supervisor (or mentor) so you can talk through the research process and any effects on you
- Don't be afraid to write, talk, and discuss your responses and seek help when it is needed

Adapted from Fahie (2014).

In Australia, Bowtell et al. (2013) have called safety protocols to include training to teach researchers about being aware of how they feel in relation to emotion saturation and tips for recognizing emotional exhaustion and strategies to reduce researcher fatigue (see Box 2). They recommend that the assessment of emotional safety risks “predate or at least be developed concurrently with the ethics application for any research project” (Bowtell et al. 2013, p. 659).

Box 2 Ten Emotional Safety Tips for Researchers

1. Researchers should acknowledge that an emotional impact is inherent to qualitative research.
2. Before applying to an HREC, the researcher and supervisory team should undertake a detailed assessment of potential risks to the emotional safety of the researcher, as well as to the emotional safety of research participants.
3. The research team should discuss the boundaries that lie between the researcher and participants and how individual researchers might maintain these while establishing rapport.
4. Research supervision should regularly include reviewing the emotional impact of the research process on the researcher through both discussion and review of field notes.
5. Supervisors should proactively arrange emotional support for researchers from a suitably qualified professional who understands the nature of the

(continued)

Box 2 (continued)

research. Regular debriefing should take place from the start of the study, rather than in response to an incident or event. To promote honest communication and uphold privacy, this person should not be a member of the research team.

6. Researchers should be encouraged to regularly practice mindfulness and engage in emotional auditing via memos or research diaries after each interview and when reviewing recordings and transcripts.
7. Researchers need to create boundaries between home and work. Having a balanced lifestyle reduces the risk of burnout.
8. Research supervisors should support the researcher to briefly “step away” from the intensity of the research process as an appropriate response to promoting emotional safety when major challenges arise.
9. Regular departmental meetings (e.g., seminar series) should encourage discussion of the emotional impact of the research on the researcher.
10. The challenging moments of research should be shared within the qualitative research community so that others can learn.

Note: HREC = human research ethics committee.

Reproduced with permission Bowtell et al. 2013.

Researchers may be well advised to participate in clinical supervision to deal with any issues that may arise throughout the research process that cannot be discussed openly with supervisors. This type of formalized supervision is now a requirement of many of the codes of ethics of professional associations across the world (Australian Guidance and Counselling Association 1997; Australian Psychological Society 2002; Australian Nursing Council 2003; International Federation of Social Workers 2006; Social Research Association 2006). It has been recommended that researchers and research institutions should also be encouraged to have arrangements for such supervision formalized within their guidelines (Bloor et al. 2007; Bowtell et al. 2013). There are a number of good examples of how supervision and support for researchers can be built into research projects. The Social Policy Research Unit (SPRU) at the University of York used a model of group psychotherapy to support researchers who were interviewing recently bereaved parents (Corden et al. 2005). Similarly, Natalie Wray et al. (2007), in their study of gynecological cancers, reported using both the university counselor for debriefing after emotionally distressing interviews and utilizing a fee-for-service psychotherapist to assist in dealing with researcher distress.

6.3 Guidelines for Transcriptionists

Transcriptionists can also be emotionally affected by the work that they do. Gregory et al. (1997, p. 297) propose the following tips for those undertaking transcription work.

- Be included in the ethics process.
- Be encouraged to have a process for self-care.
- Be fully informed of the nature of research and type of data.
- Be altered prior to the transcription of potentially ‘challenging’ or ‘difficult’ interviews.
- Have regular scheduled debriefing sessions.
- Have prompt access to an appropriate person for crisis counseling.
- Have a clearly documented process for the termination after transcription is completed that includes a resolution of personal issues that may have arisen as a consequence of the work.
- Be encouraged to journal thoughts and feelings which may then become a part of the fieldwork notes in some studies.

A discussion of these prior to undertaking any work would ensure that transcriptionists are fully prepared for the work that they do.

7 Conclusion and Future Directions

As researchers, research assistants, supervisors, and transcriptionists we need to take emotions within research seriously into account. If we do then we open a space within which we can explore practical strategies to work with our emotional responses. Like Fitzpatrick and Olson (2015), in this chapter, I have demonstrated that rather than viewing researchers’ emotions as risks to be avoided, researchers, ethics committees, supervisors, transcriptionists, and colleagues should value emotions as integral to human life and respond accordingly by encouraging researchers to reflect on their own emotions. In this chapter, I have provided a range of examples from researchers that should encourage others to consider these risks. In doing this, we bring to light aspects of our experience that may be particularly problematic for novice researchers or those researching sensitive topics. I have outlined the need to put in place process and policies to protect **all** members of the research team from both physical and emotional harm and provided a number of tips to assist. By doing this, we create an environment where both researchers and supervisors feel able to talk about challenging issues and devise strategies to ameliorate any risks. As part of this, it is important for us to incorporate discussions of psychological well-being and emotional risk into professional development and research coursework programs and to demand that formalized guidelines are developed that address all harms that researchers may face.

Future directions for research in this area should include more empirical work that documents the experiences of researchers and others in the research team involved in a range of qualitative projects. With further evidence of the risks inherent in this research, a comprehensive and universal standard of minimum policy requirements can be developed. This type of policy could be implemented by researchers, ethics committees, research institutes and universities to ensure the emotional and physical safety of those involved in research is protected.

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Doing Reflectively Engaged, Face-to-Face Research in Prisons: Contexts and Sensitivities 124

James E. Sutton

Contents

1	Introduction	2164
2	Contextualization of Research with Prisoners in Prisons	2166
2.1	The Nature of Prisons	2166
2.2	The Nature of Prisoners' Lives	2167
2.3	Sensitive Contexts for Researchers	2168
3	Ethical Considerations	2170
3.1	Formal Review Boards	2171
3.2	Beyond Formal Review Boards	2172
4	Doing Reflectively Engaged Prisoner Research	2173
4.1	Managing Boundaries and the Presentation of Self	2174
4.2	Emotional Management	2175
5	Conclusion and Future Directions	2175
	References	2176

Abstract

This chapter begins by establishing an historical trajectory of face-to-face research with prisoners. It goes on to identify fundamental features of prisons and prisoners' lives that make them sensitive settings and populations for researchers to study, and it then presents ethical considerations that researchers must be mindful of when carrying out this kind of research. Ethical concerns both within and beyond the scope of formal Institutional Review Boards are outlined and explored, as are researcher strategies for managing boundaries and emotions when doing prison research. To the extent that ethics, emotions, researcher presentation of self, and similar themes have been written about within the context of prison research, they have primarily been framed as considerations

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for qualitative field researchers. By way of contrast, an underlying assumption of this chapter is that those who do other forms of face-to-face research with prisoners, including quantitative self-report surveys, mixed-method approaches, and focus groups, should similarly engage with these themes. This chapter ultimately endorses being reflectively engaged with the setting, the research process, and oneself when doing face-to-face research in prisons, regardless of the substantive goals of one's study or the particular research methods one employs. Accordingly, the issues raised in this chapter will be relevant to a range of health and social science researchers who enter prisons to study prisoners.

Keywords

Prison · Corrections · Research ethics · Sensitive research · Reflexivity · Total institution

1 Introduction

Systematic, face-to-face observation within prisons dates back to when John Howard visited over 200 European prisons in the 1700s and then reported on their abhorrent conditions (Howard 1780). The first prison-based research projects in the United States began to emerge in the early-to-mid 1900s, including Joseph Fishman's expose of sexual behavior and abuse in prison (Fishman 1934), Donald Clemmer's ethnography of prison culture (Clemmer 1940), and Gresham Sykes' examination of how prisoners respond to deprivations and totalitarian power (Sykes 1958). A recurring theme in these early prison studies was the illumination of harmful prison conditions, often for the purpose of promoting penal reform.

US prisoners were studied by ethnographers and others more frequently in the 1960s and 1970s. However, there was subsequently little ethnographic prison research being conducted when the US prisoner population was growing exponentially in the 1990s and early 2000s (Wacquant 2002; Reiter 2014). This was in large part due to more formal restrictions being placed on prison research beginning in the 1970s (Wakai et al. 2009; Cislo and Trestman 2013). Most recently, the past decade has seen a resurgence of critically engaged prison ethnography, with much of the contemporary work occurring in Europe (Reiter 2014; Drake et al. 2015).

The world's prisoner population has been growing rapidly and significantly, with an unprecedented 10.35 million people now incarcerated worldwide (Walmsley 2013). The United States imprisons approximately 2.2 million of these prisoners (Kaeble et al. 2015), making it the world's leader in the use of incarceration. Despite the notable growth in incarceration in recent years, we know less about the lives of prisoners than we do about people in free society (Cislo and Trestman 2013). Hence, there remains a current need for more research in prisons given the number of people who now experience incarceration firsthand. Similar to the early prison studies that were referenced in the opening paragraph, further research can be used to highlight harmful conditions in modern prisons and to ultimately support reform efforts.

Prison research can also help to better understand afflictions that are common among prisoners (Brewer-Smyth 2008) and to inform responses to other problems that extend beyond prison walls. The fact that most prisoners will ultimately be released is typically an afterthought, yet the sheer number of individuals who now cycle in and out of correctional facilities puts myriad strains on the community (Petersilia 2009). For instance, returning prisoners bring home high rates of infectious disease upon release (Bick 2007; Brewer-Smyth 2008) and have ongoing struggles with addiction and drug-related offending (Hser et al. 2007). Insights gained from doing research with prisoners can potentially guide efforts to alleviate these kinds of problems.

In many jurisdictions, crime policy has increasingly become more interlaced with social policy. Accordingly, whereas prison researchers have historically been criminologists and sociologists, the current nature of incarceration now brings researchers from a broader range of health and social sciences into prisons to conduct research. Whether the purpose is to expose oppressive prison conditions (Ross and Richards 2003), to conduct epidemiological research (Johnson et al. 2015), to examine romantic relationships between prisoners and those on the outside (Comfort 2008), or to pursue some other objective, this is a dynamic time for prison-based research. Moreover, although ethnography has traditionally been the conventional research strategy used in prison environments, other face-to-face methods including surveys (Sutton 2011), mixed method approaches (Harvey 2007; Jenness 2010), and focus groups (Naylor 2015) are now also being used more frequently (see also ► Chaps. 4, “The Nature of Mixed Methods Research,” ► 27, “Institutional Ethnography,” and ► 33, “Epidemiology.”).

Simply put, the backgrounds, objectives, and methods of prison researchers today are more diverse than they were in the past, and recent incarceration trends are likely to sustain the current resurgence of prison research into the future. Toward this end, this chapter provides an overview of common issues that emerge when doing face-to-face research with prisoners in prisons. As has typically been the case within the literature, the focus here is primarily on issues that have been pertinent to prison research conducted in the USA and other English-speaking nations (see Cunha 2014, for an examination of prison ethnography in a broader global context).

A number of ethical and practical considerations are introduced, and a case for reflectively engaging in the research process is put forth. One of the reasons for writing reflectively about carrying out research is that it can potentially be helpful for future researchers (Sutton 2011; Jewkes 2012). The intended audience for this chapter is, therefore, novice researchers from a range of health and social sciences, although more seasoned prison researchers will likely benefit from this overview as well. Although ethnographic themes are prevalent, this chapter is ultimately geared toward those who engage in any form of face-to-face research. A guiding premise is that the unique and sensitive nature of studying prisoners has implications for all researchers, irrespective of the particular methods they might use. I turn now to outlining fundamental features of prison contexts that researchers should be mindful of.

2 Contextualization of Research with Prisoners in Prisons

Prisons are complex environments, and prisoners' lives are complicated. Each of these dynamics poses unique research challenges in its own right, and when they converge the difficulties are further compounded. Downing et al. (2013, p. 493) propose "distinguishing between foreground and background dynamics. Foreground dynamics involve the physical, practical elements of a research space. . . and background components involve the lived realities of respondents." Put another way, those doing face-to-face research with prisoners must take the natures of prisons and prisoners' lives into account when developing their research designs, collecting data, and contextualizing their findings.

2.1 The Nature of Prisons

Researchers working in prisons need to be cognizant of forces that operate on the organizational and meso levels within these environments. Prisons are total institutions, which can "be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman 1961, p. xiii). Aside from prisons, other common examples of total institutions include mental hospitals and immigrant detention centers. Regardless of the specific organizational context, inmates in these kinds of settings similarly become subservient to the routines and external social controls that structure their daily lives.

Prisons are ultimately bureaucratic organizations that prescribe positive behaviors, proscribe negative conduct, and comprise webs of interactions based on formal statuses and roles (Hart 1995). Accordingly, as is the case with other bureaucratic organizations, prisons are often experienced as impersonal, disempowering entities by the individuals who are found within them. The organizational practices and routine activities of those who work in total institutions reinforce us/them divisions between staff and prisoners, which often lead to inmates being treated as though they were objects rather than humans (Goffman 1961). Within this context, imprisonment and detachment from free society result in pain and deprivation, as inmates lose the privacy, agency, security, and intimacy with others that are often taken for granted in the broader community (Sykes 1958).

These preceding observations establish a conceptual foundation from which incarceration can be better understood. There are also a number of more specific stressors commonly found in prisons that vary in magnitude from one institutional setting to the next. For instance, prisons can be barren, noisy, and musty places, which can be arduous for prisoners and staff to endure over time. Poor confinement conditions, such as inadequate ventilation and overcrowding, result in further discomforts and in some cases can even facilitate the spread of disease (Hoge et al. 1994; Coninx et al. 2000). When compared to other kinds of research settings, prisons feature more pronounced effects of the research environment on the researched given that they are closed systems that restrict movement (Johnson 2015).

The most challenging stressor for many prisoners is navigating the inmate social order. Clemmer (1940) and Sykes (1958) were the first scholars to outline the central tenets of the inmate code, which tend to be organized around toughness, antagonism toward prison staff, and the enforcement of the unofficial normative systems developed by prisoners. Violence, victimization, gang activity, and other forms of deviance are now often intertwined with the inmate social order, and hence they pervade the public spaces within many correctional facilities (Johnson 2002). Inmates learn how to survive in the face of these complex forces and are otherwise socialized into the prison culture through the process of “prisonization” (Clemmer 1940). The nature of prisons and the prisonized ways in which inmates adapt can, therefore, add further complication to prisoners’ lives.

2.2 The Nature of Prisoners’ Lives

Prisoners are diverse, and they end up in prison for a variety of reasons. Nonetheless, for prisoners as a group, there are a number of recurring themes in their lives that put them at greater risk for involvement with the criminal justice system and related problems. Those who do prison research should, therefore, be equipped with a working sense of what prisoners’ lives entail.

Generally speaking, cumulative social disadvantage is prominent within the prison population. Prisoners as a group feature high likelihoods of coming from impoverished communities and families, have low levels of educational attainment, face poor job prospects, experience stigma in the community, tend to come from disadvantaged class and race backgrounds, and are often low in cultural capital (Western and Pettit 2010). Many have also been physically and/or sexually abused when they were children (Brewer-Smyth 2008), suffer from serious mental illnesses (Fazel and Seewald 2012), and contend with physical illnesses and diseases (Bick 2007; Johnson et al. 2015). Substance abuse is a common coping strategy for prisoners (Brewer-Smyth 2008). It is, therefore, unsurprising that a systematic review of prior studies found that 10–48% of male prisoners had drug problems upon coming to prison, which is a higher rate than is found among the general population (Fazel et al. 2006).

Several foreground and background characteristics that are common in prisons and prisoners’ lives have now been presented. It is important to recognize that, in practice, these dynamics are often mutually reinforcing. For instance, a preexisting mental illness might be aggravated by the routine procedures of total institutions. Or, new mental anguish may emerge upon experiencing the deprivations of confinement for the first time or after having been victimized by other inmates. Similarly, racial or other tensions might be triggered by the stresses of living in overcrowded facilities or by adherence to precepts of the inmate social order. The nature of these dynamics and intricacies of their interconnections illuminate some of the reasons why prisoners can be sensitive populations to study and prisons can be sensitive settings in which to study them.

2.3 Sensitive Contexts for Researchers

Whether unnoticed or blatant, the patterned interactions, power hierarchies, objectification, and other features of total institutions are ubiquitous when doing face-to-face research with prisoners in prisons. Those who have yet to do this kind of research may have trouble fully appreciating the ways in which these dynamics come into play when collecting data. Several examples from both my own work and the works of other researchers are, therefore, provided in this section to further underscore the uniqueness of doing research in these settings.

As formal bureaucratic organizations, prisons prioritize their own organizational goals over the objectives of researchers (Hart 1995; Sutton 2011; Sloan and Wright 2015; see also ► Chap. 125, “Police Research and Public Health”). Preserving institutional security is the primary mission for those charged with operating prisons (Hart 1995; Wakai et al. 2009; Beyens et al. 2015), and toward this end schedules, rules, and routines are regularly adhered to in order to maintain order. This can have unintended consequences for researchers who are trying to complete crucial steps in the research process. A few examples of how organizational practices can obstruct meetings with interviewees are instructive.

When doing research in US prisons, I frequently encountered challenges upon my arrival due to the front desk staff not having received the correct paperwork to grant me admittance (Sutton 2011). I had little recourse in these instances. Staff members at the entrance were similarly powerless, even though in many instances these same staff members knew what I was doing, knew that my project had been approved by the prison system, and had allowed me in just the day before and on dozens of other occasions. Another researcher found that “inmates are reluctant to participate [in research] if it means they will miss the opportunity to participate in work or educational programming for the day...this can result in refusal to participate altogether” (Downing et al. 2013, p. 488).

These two examples demonstrate how research is secondary to and often trumped by organizational routines and procedures. Prisons differ from other sites in that the researcher is dependent on the organization when carrying out the research (Newman 1958). While one might correctly observe that researchers who do field work in other settings lack control over the situations that emerge during the research process, researchers in prisons and other total institutions are unique in that they actually cede control to a more powerful actor in order to accomplish integral research tasks.

Sometimes, the inherent power disadvantage between researchers and staff manifests itself in surprising ways. When doing research in a prison, the individuals within the organization that are familiar with the researcher’s project and who grant approval are usually administrative staff who are removed from the prison’s daily activities. The prison employees that researchers usually interact with on a regular basis typically have little understanding of the researcher’s protocol or research procedures in general. This can produce unique and unexpected challenges.

For instance, staff members might take the initiative to arrange meetings for the researcher with prisoners that the researcher had not been planning to talk with

(Naylor 2015). In my own research, I had a few times when staff members suggested that I interview prisoners that they thought could be interesting. On other occasions, they arranged to have multiple people come to meet with me at the same time to help with efficiency, despite the fact that my project required me to meet with interviewees individually. These kinds of seemingly innocuous incidents can result in tensions if staff members who are genuinely trying to help feel that their efforts are unappreciated or if prisoners feel disrespected due to their routines being unnecessarily disrupted. These examples underscore the inherent lack of control that researchers have over the research process when they cede power to the institution, irrespective of the intentions of the individuals who then enact that power.

Given the emphasis on order in prison, an implication for researchers would be to take efforts to fit into the routine. However, this can be complicated in practice due to us/them dichotomies between staff and inmates that are inherent in total institutions (Goffman 1961; Sutton 2011). Within a closed, formally structured system, where do researchers who are neither “us” nor “them” fit in? As previously noted, researchers are dependent on staff to facilitate access to prisoners and assist with other logistics. Researchers, therefore, need to maintain positive relations with staff, although this can potentially be detrimental to the research if prisoners perceive the researcher to be on the side of the prison. At the same time, researchers need to establish trust with inmates that they are collecting information from, which can hinder working relationships with staff who view the researcher as being on the side of prisoners.

Balancing loyalties while maneuvering within the power structure of a total institution can be trying for those who do face-to-face research in prison. However, the most difficult part of collecting data in these settings for many researchers is being exposed to prisoners’ lived realities firsthand. I have previously written about my own experiences of feeling powerless when seeing inmates who were isolated from free society being dehumanized within a total institution (Sutton 2011). Being unable to provide direct assistance to people who are in need can also be distressing, as Bosworth and Kellezi (2016) experienced when doing research in an immigrant detention facility in Britain.

Those who are preparing to do research with prisoners should expect to encounter a diverse group. Whereas some prisoners will not exhibit any visible indicators of pain, there will be others whose problems are immediately clear. Demeanor, facial expressions, and disposition often hint at foreground stressors associated with incarceration. I have also done interviews with a handful of prisoners who had bruises, self-cutting scars, and other embodiments of foreground and background trauma. Additional inmate challenges such as language barriers, being illiterate, being low in cultural capital, and being under the influence of psychotropic drugs tend to become apparent through interaction. In sum, the cumulative disadvantage commonly found among the prisoner population is often easy to see when doing face-to-face research in prison.

An issue that has not yet been addressed is the possibility of danger to researchers in prison. Brewer-Smyth (2008) notes that three potential harms that researchers might encounter in prison are disease, physical violence, and psychological distress

when being exposed to prisoners' pain. She concludes that the likelihood of experiencing psychological distress is much higher than the chances of contracting a disease or being assaulted. There are certainly many dangerous people in prison, although violence toward researchers is not among the prevalent themes in the literature. But with this said, Lonnie Athens was once intentionally locked in a cell with a dangerous prisoner who was not on his interview list (Rhodes 1999, p. 51). Athens was set up by staff in this particular instance, which is an extreme example of how researchers can encounter problems when navigating us/them divisions in prison.

As should now be clear, doing face-to-face research in prison is a visceral experience (Jewkes 2012). The selected examples that have been provided up to this point are in no way exhaustive, but they are nonetheless indicative of the types of dynamics that emerge when doing research in a complex environment with people who have complicated lives. Furthermore, it must be noted that many of these dynamics occur simultaneously. It is, therefore, crucial for researchers to have a sense of these themes prior to carrying out their research. Researchers should also have an understanding of common ethical dilemmas that emerge when engaging with the sensitivities associated with prisons and prisoners' lives.

3 Ethical Considerations

Prisoners are vulnerable to coercion given their inherent powerlessness within total institutions. There is a long history of prisoners being exploited by researchers and used in experiments that would now be considered unethical by today's standards, including high-profile abuses that were carried out under the Nazi regime (Wakai et al. 2009; Cislo and Trestman 2013). Prisoners have often served as a convenient pool of research subjects over the years. For instance, in the mid-1900s prisoners were used in the majority of trials for new drugs leading up into the 1970s (Cislo and Trestman 2013).

The 1970s marked a pivotal time for research, as formal guidelines and review boards increasingly emerged to protect the rights of prisoners and other research subjects (see also ► Chap. 106, "Ethics and Research with Indigenous Peoples"). Some have argued that prisoners have now actually become "overprotected" and "understudied" in more recent years as a result (Wakai et al. 2009; Cislo and Trestman 2013; Johnson et al. 2015). The U.S. Department of Health and Human Services released the Belmont Report in 1979, which is a document that specifies ethical principles and guidelines for protecting human subjects when doing research (US Department of Health and Human Services 1979). In spirit, the Belmont Report is consistent with the Nuremberg Code that was prepared during the time of the Nuremberg trials (Cislo and Trestman 2013). In practice, these two documents feature several overlapping recommendations for conducting ethical research.

The Belmont Report stipulates that individuals who are being studied must be made aware of the potential risks and benefits of their research participation. They must ultimately give informed consent before participating, and their participation

must be voluntary. Moreover, consent must be free of undue influences or rewards that could potentially compel participant acquiescence, and participants must additionally be given the right to withdraw from participating at any time. The Belmont Report recognizes that the ability to agree to participate in research may be affected by factors such as age, developmental maturity, and incarceration, and it, therefore, calls for special efforts to be taken towards protecting prisoners, children, and other vulnerable populations. Formal institutional review boards now routinely screen research proposals to ensure that they comply with the stipulations outlined in the Belmont Report and other ethical standards (see also ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)).

3.1 Formal Review Boards

Ethical standards for research in the USA and many of its peer nations in the English-speaking world are typically maintained by formal review boards that operate within universities and similar settings in which researchers work. Institutional review boards in the USA are required to have a prisoner or prisoner representative participate when proposals involving prison research are reviewed (Brewer-Smyth 2008; Wakai et al. 2009). University researchers who work with human subjects are likely accustomed to securing review board approval from their places of employment. However, some may not realize that when doing prison research, there is typically a second formal review board administered by the prison system that will also need to grant approval before research can be conducted (Wakai et al. 2009). Prison researchers must, therefore, satisfy multiple gatekeepers in order to conduct research in prison (Naylor 2015).

Moreover, some funding agencies may require additional steps before research can commence. For instance, researchers doing studies supported by the U. S. Department of Health and Human Services (DHHS) are required to get a DHHS prison certificate that verifies that the project adheres to DHHS standards (Brewer-Smyth 2008). Along these lines, US researchers can also apply to the National Institutes of Health for a Certificate of Confidentiality (Wolf et al. 2004; Brewer-Smyth 2008). Certificates of Confidentiality legally protect researchers from having to provide identifying information about their research participants to authorities, and researchers’ applications for Certificates of Confidentiality are rarely rejected in practice (Wolf et al. 2004). In my own research, I have found that having a Certificate of Confidentiality helps prisoners feel more comfortable about their participation.

A dilemma that often comes up in prison research is whether or not to compensate participants. This issue raises concerns about undue influence as spelled out in the Belmont Report. Monetary compensation is generally not permitted, nor are prisoners allowed to use their research participation to garner favor in parole hearings (Wakai et al. 2009; Waldram 2009). In my own research, I had hoped to be able to provide participants with a candy bar or similar item from the prison vending machine to thank them for their time. However, this request was not allowed by the prison’s review board. As Brewer-Smyth (2008, p. 123) correctly observes, shampoo and other “low-cost items that can be purchased for less than \$5 per inmate may

seem to be so great to the inmate that his or her ability to weigh the associated risks becomes impaired because of the restricted prison environment.” Setting concerns about undue influence aside, providing compensation to participants might also cause management problems for prisons. For instance, institutional security could potentially be threatened if prisoners who are not invited to participate in research perceive that other inmates are receiving special treatment.

Whereas formal review boards help researchers ensure that their projects are in compliance with ethical standards, their demands may inadvertently introduce methodological challenges to research designs. For instance, review boards may ultimately determine, and thereby limit, the specific institutions that researchers visit or the actual prisoners that researchers interact with. For quantitative researchers, this can hinder probability sampling and, therefore, jeopardize generalizability. Qualitative researchers face their own challenges. For instance, review boards often require that researchers submit a list of questions that will be asked before a project can be approved. However, this demand is problematic for phenomenological researchers who rarely know the exact direction that their research will take prior to entering the field (Easterling and Johnson 2015).

3.2 Beyond Formal Review Boards

The formalized standards of review boards are reified through their enforcement and the compliance that they command. One result of this is that newer researchers may assume that ethical considerations have been satisfied once review board standards have been met. This is an erroneous assumption. When doing face-to-face research with prisoners in prisons, a number of additional, unanticipated ethical challenges often emerge that fall beyond the purview of the review board process.

For instance, it was previously noted that some prison staff may take it upon themselves to help researchers without first consulting with them. This potentially raises an ethical dilemma given that these staff members are unlikely to follow proper researcher protocol when attempting to help with research tasks. It was also previously noted that prisoners as a group are low in cultural capital. One might ponder whether this poses an ethical dilemma if participants have a limited understanding of the research process. Bosworth and Kellezi (2016) struggled with this issue when realizing that the detained immigrants that they studied had “unrealistic expectations” about the extent to which the researchers could help them.

I have previously written about the possibility that loneliness might constitute an undue influence when doing prison research (Sutton 2011). Prisons, and therefore prisoners, are often located far from prisoners’ home communities, which can result in prisoners having few or no visitors from the outside world (Sutton 2011; Downing et al. 2013). Prisons are also dull and monotonous places (Martin 2000). As has already been shown, it is assumed that items like candy bars and small bottles of shampoo can influence one’s ability to make a free decision to participate in research within the restrictive prison environment. It, therefore, seems plausible that opportunities to interact with researchers could similarly compel participation from

prisoners who are regularly deprived of stimulation and contact with individuals who are not of the prison.

These select examples are intended to demonstrate that the ethics of doing research with prisoners in prisons are not always clear, nor can every ethical consideration be addressed prior to actually carrying out the research. Moreover, good ethical practice in nonprison settings does not always serve researchers and participants well within total institutions. For instance, administering written consent forms to participants is a standard practice that is typically required when gaining informed consent, with the researcher and participant then each retaining a copy of the signed consent form for their records (see ► [Chap. 106, “Ethics and Research with Indigenous Peoples”](#)). However, the detained immigrants who participated in Bosworth and Kellezi’s research were often uncomfortable signing their names (Bosworth and Kellezi 2016). Naylor (2015) encountered similar challenges and observed that having a signed consent form can potentially put one at risk within the prison environment.

It is imperative that prison researchers think critically about the ethics of what they do on an ongoing basis, and they should take special efforts to consider how the natures of prisons and prisoners’ lives pose unique ethical challenges. Formal guidelines and review boards help with addressing many crucial concerns. Yet, they do not anticipate every ethical dilemma that will emerge when doing research. Moreover, in some cases, they may even have problematic applications when their stipulations are applied to face-to-face research with prisoners in prisons. For these reasons, it is crucial for those who do this kind of research to be flexible and reflectively engaged in their work.

4 Doing Reflectively Engaged Prisoner Research

As the previous sections convey, conducting face-to-face research with prisoners is challenging and unpredictable. A number of sensitive issues arise when doing this kind of research, including unanticipated ethical dilemmas. It is beyond the scope of this chapter to present a comprehensive list of suggestions that addresses all of the considerations one must account for when doing prisoner research (see King and Liebling 2007 and Sutton 2011 for thorough lists of practical recommendations). This chapter instead advocates more broadly for adopting a reflectively engaged approach when doing research in prisons.

To the extent that ethics, researcher presentation of self, emotions, and similar themes have been examined in the prison research literature, they have primarily been framed as considerations for ethnographers. Reflexivity, which “involves developing a consciousness of one’s self in the process of research” (Drake et al. 2015, p. 11) similarly tends to connote qualitative field research. Yet, in practice, those who do other forms of face-to-face research with prisoners, including quantitative self-report surveys, mixed-method projects, and focus groups, also deal with these themes (Sutton 2011). Being reflectively engaged with the setting, the research process, and oneself can, therefore, benefit any researcher who studies prisoners in prisons, regardless of the substantive goals of his or her study or the particular

research methods that he or she employs. The following explorations of strategies for managing boundaries and emotions model themes of reflective engagement when doing prison research.

4.1 Managing Boundaries and the Presentation of Self

The question of where researchers who are neither “us” nor “them” fit into us/them dichotomies was posed earlier in this chapter. The answer will likely depend on factors such as the goal of the project, if one is studying prisoners, staff, or both, and whether one is doing ethnography or having one brief interaction with interviewees. Setting these kinds of considerations aside, some helpful insights can be derived from examining how other researchers have balanced this tension.

One strategy for managing these boundaries is to take turns focusing on and connecting with each side (Liebling 2001; Beyens et al. 2015). This approach might entail embracing each side as situations dictate (Nielsen 2010), or a researcher could start with one side and then shift to the other (Beyens et al. 2015). An advantage of managing boundaries by taking both sides at various points would be having an opportunity to gain multiple perspectives, while downsides would include the effort this would entail and the potential for backlash from the first side after transitioning to the second.

Another strategy is to embrace an outsider status (King 2000). I have taken this approach in my own research, and doing so allowed me to gain invaluable insights (Sutton 2011). I took the advice of other researchers and emphasized the fact that I was not connected to the prison system (Newman 1958). For instance, I made sure to engage in acts such as waiting for escorts to ensure that my outsider status was clear (King 2000; Johnson 2015).

I also emphasized the fact that I was there to learn rather than to advocate for either prisoners or staff (King 2000). Toward this end, I introduced myself as a researcher rather than a criminologist because I feared that the word criminologist might have a negative connotation. When researching detained immigrants, Bosworth and Kellezi (2016) encountered respondents that were put off by the fact that they were being studied by criminologists despite not having done anything wrong. The criminologist title implies law enforcement to some and prisoner advocate to others, so I found that embracing the university researcher label worked best. Others have similarly noted that being connected to a university increases the likelihood of being taken seriously by prisoners and staff in prison settings (Newman 1958; Jacobs 1977; King 2000; Martin 2000).

Within a closed system that is structured around power hierarchies and formal roles, researchers will inevitably be categorized by those who inhabit the system. Being reflectively engaged in the research process can, therefore, enable researchers to exercise more agency over how they are ultimately placed. Moreover, being reflectively engaged can also help ensure that researchers select the most fitting presentation of self for their purposes given that what constitutes best practices in this line of research is often situational. Having to manage these kinds of boundaries

is among the reasons why establishing connections to those being researched in prisons can be especially difficult when compared to doing research in other environments (Brewer-Smyth 2008; Waldram 2009).

4.2 Emotional Management

Along with managing boundaries and impressions, those who do prison research also need to engage in emotion management when they are in the research setting and potentially when they are thinking about their research at other times (Nielsen 2010; Sutton 2011). In recent years, there have been several written accounts of the emotional experiences of field researchers who work in prisons. This is a positive trend given that future researchers can learn from reading about the emotional experiences of those who have come before them (Liamputtong 2007; Sutton 2011; Jewkes 2012; see also ► Chap. 123, “Emotion and Sensitive Research”).

Spending time in a prison can result in intense emotional experiences (Wacquant 2002; Jewkes 2012). It is, therefore, crucial for researchers to remain reflectively engaged in what they are doing because intense emotion can cause distress when researchers are exposed to trauma and other unsettling realities found in prison (Brewer-Smyth 2008). Moreover, researchers who react to their emotions when doing face-to-face research in total institutions also run the risk of making their interviewees uncomfortable. For instance, an intense reaction to something shared may cause the interviewee who shared it to stop talking (Bosworth and Kellezi 2016). An effective strategy for reflective engagement on an emotional level is to have regular conversations with close colleagues who can provide support, give advice, and identify instances where the researcher has become too immersed (Sutton 2011; Liebling 2014; Beyens et al. 2015). On a final note, researchers should ultimately keep in mind that their exposures to these settings are temporary and voluntary and come with the option to withdraw at any time, which is not the case for prisoners and staff (Drake et al. 2015).

5 Conclusion and Future Directions

This chapter’s primary goal has been to make the process of doing research with prisoners in prisons accessible for a general health and social sciences audience. It has provided overviews of the nature of prisons and prisoners’ lives while highlighting research sensitivities and exploring ethical implications. A reflectively engaged orientation has ultimately been endorsed for the purposes of helping researchers identify, manage, and resolve the complex and complicated issues that regularly emerge when doing this kind of research.

Although prisons and prisoners are diverse, there are recurring themes when researching prisoners in prisons. For instance, prisons are emotionally charged places and prisoners’ lives tend to feature cumulative foreground and background disadvantage. Moreover, structural power dynamics and ethical dilemmas are

inherent in research in prisons and other total institutions, and the research process is often unpredictable. Accordingly, aspiring prison researchers should learn about other researchers' experiences as part of a broader effort to be as prepared as possible (Sloan and Wright 2015). Prison researchers should also plan for the unexpected (Sutton 2011), and toward this end, they should be dynamic, spontaneous, and flexible (Martin 2000; Johnson 2015). Finally, and most basically, those who do research with prisoners in prisons should "plan to learn more than [they] envisioned" (Sutton 2011, p. 58).

Two general conclusions about future directions for prison research can now be derived from the preceding sections. First, there will likely be an uptick in research done in prisons given that the World's prisoner population has been growing. If incarceration continues to expand, there will inevitably be more people subjected to the problems associated with imprisonment. This should in turn bring researchers from an increasingly broad range of disciplines into prisons as they work to develop solutions.

Second, and also relative to the past, future prison research will be more diverse in terms of researchers' backgrounds, objectives, and methods. Research in prison has its origins in the ethnographic tradition and in fields such as criminology and criminal justice. These methodological and disciplinary boundaries will need to become more encompassing in order to better illuminate harmful conditions and facilitate penal reform. This brings me to a final conclusion, which is that researchers who study prisoners in prison will need to increasingly focus on identifying common challenges, refining best practices, and engaging in scholarly dialogue as they carry out this work.

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Police Research and Public Health

125

Jyoti Belur

Contents

1	Introduction	2180
2	Researching Public Health in Policing	2181
3	Unpicking the “Hard-to-Reach” Nature of Police Organizations: Barriers to Police Research	2183
3.1	Cultural Barriers	2183
3.2	Divergent Aims	2184
3.3	Lack of Trust and Cross-Cultural Communication	2184
4	“Who Is the Researcher” and “What Is Being Researched”? Important Questions in Police Research	2185
5	Moving from the Personal to the General: Lessons Learnt from Doing Police Research	2187
5.1	Negotiating Access	2189
5.2	Agreement on Research Objectives	2190
5.3	Establishing Trust	2190
5.4	Knowledge Exchange and Dissemination	2191
6	Conclusion and Future Directions	2192
	References	2193

Abstract

This chapter examines the challenges involved in conducting face-to-face research with police officers with respect to their work in sensitive areas or with hard-to-reach populations. The intersection between law enforcement and public health is drawing greater academic attention through the concept of harm reduction policing (Ratcliffe 2015). The refocusing of police attention from concentrating purely on crime to reducing harmful effects on individuals and the community has created an emerging social space that needs further exposition.

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The changing nature of policing and a rise in societal demands for security has increased the overlap between law enforcement and public health. This chapter lays down some basic guidelines to aid researchers operating in this space based on the author's personal experience and drawing upon the research experience of others working in this area. It begins by identifying fundamental features of policing culture that make it a sensitive organization to access and research. It then discusses the difficulties in approaching gatekeepers and negotiating access to police data and individual officers. The discussion then focuses on the experience and implications of researching the police organization as an insider and/or as an outsider (Brown 1996). Finally, ethical and practical considerations involved in carrying out this kind of research are discussed.

Keywords

Public health research · LEPH · Police research · Access negotiation · Research aims · Researcher status

1 Introduction

This chapter examines the challenges involved in conducting research in areas where policing and public health protection intersect. The overlap between law enforcement and public health is drawing greater academic attention through the concept of harm reduction policing (Ratcliffe 2015). The refocusing of police attention from concentrating purely on crime to reducing harmful effects on individuals and the community has created an emerging social space that needs further exposition. The changing nature of policing and a rise in societal demands for security have increased the overlap between law enforcement and public health. The domains of policing and public health intersect at the point where the state is concerned with the promotion of healthy lifestyles, protection of the vulnerable, and injury prevention. Securing certain aspects of the public health agenda depends on co-operation from the police and other arms of law enforcement. The police, in turn, need public health systems and structures to deal with complex social issues involving prevention of violence, injury, and social harms. The key elements uniting both disciplines are the shared objectives to protect the public and promote harm reduction.

However, this interdependence has not always been recognized by the police or public health authorities. Traditionally, the police have concerned themselves with patrol, investigation and detection of crime, maintenance of law and order, and public security. Protecting and promoting public health has not been high on their agenda of priorities or their self-identity (Van Dijk and Crofts 2016), even though they are responsible for preventing harm and securing well-being of populations, which, among other things, is squarely within the purview of public health (WHO 1948). Recently, there has been a spate of arguments for the two fields to recognize their interdependence in protecting the population's well-being and there are calls for both communities to work together as frontline organizations in providing direct interventions to securing health and ameliorating risky behaviors

(see Van Dijk and Crofts 2016 for a summary). The police mission has expanded to include crime control and order maintenance with social service (Millie 2013). Concurrently, increasing focus on “victims” and “vulnerable people” for law enforcement has brought a whole range of public health related issues such as domestic violence, violence in public places, human trafficking, prostitution, and mental health under the purview of policing policy and practice (Van Dijk and Crofts 2016). Conceivably, the concept of vulnerability will bridge the existing gap between health and police sciences (Bartkowiak-Théron and Asquith 2016; see also ► Chap. 110, ““With Us and About Us”: Participatory Methods in Research with “Vulnerable” or Marginalized Groups”).

Evidence indicates that the police can help or hinder access to resources and efforts made by public health organizations and NGOs working, for example, in the area of HIV prevention with sex workers and drug addicts to promote public health addicts (Open Society Foundation 2014). Using a recent example of research on the relationship between public health objectives and policing conduct with respect to drug taking behavior, Hayashi et al. (2013) suggest that the police treatment of drug addicts and drug enforcement policies can affect whether the public health agenda of reducing drug misuse is achieved or not. More often than not, public health and law enforcement agencies work in silos and do not share conceptual frameworks and practice synergies that arise from the expertise, skills, and knowledge of each other’s personnel (Bartkowiak-Théron and Asquith 2016).

The intention here is not to reiterate the case for why law enforcement and public health agencies must collaborate, but to suggest that the two fields intersect and, therefore, research at these points of conjunction needs to be interdisciplinary. However, as with practitioners, researchers in both sciences remain experts in their particular domain and, therefore, find it difficult to research the interconnections. This chapter explores challenges for public health researchers working with law enforcement.

2 Researching Public Health in Policing

The crossover between law enforcement and public health, termed as LEPH, is attracting academic and practitioner interest in recent years (Punch and James 2016) but remains a fledgling field of research. More traditional public health-related research in policing mainly explores how police misconduct or negligence actually can cause public health hazards, for example, police shootings (excess use of force), custodial violence, or negligence. Further, a substantial section of public health research on policing issues explores the victim’s perspective on police response or behavior focusing on provision of police service to victims of drug abuse (Maher and Dixon 1999; Cooper et al. 2004) or rape (Jameel 2010). There are a few examples of public health research done with police officers exploring police perspectives on public health-related issues which include evaluations of interventions, for example, in cases of domestic violence (Hovell et al. 2006). Even these projects did not generally involve primary research with the police, but working with

police records and open-source crime data. Similarly, other public health-oriented research is focused on how the police can aid or mar efforts to improve public health and safeguard community security. The benefits of such cross-disciplinary research seem to be focused on how police actions are currently detrimental to public health (Maher and Dixon 1999; Kerr et al. 2005), and policy implications are discussed in terms of what the police should be doing in order to improve public health.

The benefits of such research for public health are clear. Perhaps this might be the direct result of the fact that public health scholars researching the police are clearly focused on public health outcomes of their research. However, the other side of the equation remains largely neglected, i.e., how can this research be beneficial for the police? This is not to assert that improving public health is not in the interests of the police, but perhaps the dearth of police researchers getting involved in research that has public health implications has meant that these issues are not viewed from the perspective of the police.

It follows that most public health research on the police is in the “critical research tradition,” which “prides itself on its detachment and independence from the police as subject matter, and, almost always, manages to find fault with rather than celebrate the role and activities of the public police. It does not seek to directly change the police but to contribute through its expert voice and publications to the thinking of governments and legislators” (Bradley and Nixon 2009, p. 423). Most of this research is “on” the police rather than “with” the police (Cockbain and Knutsson 2015). Unsurprisingly, police leaders are deeply unhappy and nervous about the “spirit and tenor” of such critical research (Young 1991).

The police are traditionally considered to be a closed organization and difficult to access (Skolnick 1975; Punch 1989). Access to organizational knowledge can be of two kinds: documentary data, in the form of official statistics; and documents or experiential data, embedded in surveys and interviews. While on the one hand, the police are heavily bound by restrictions of data protection legislation in most Western democratic countries, limiting both their ability and desire to give access to sensitive data. On the other hand, access to experiential data, in the form of ethnographies or interviews with police officers, is equally difficult. Negotiations have to be conducted not only with gatekeepers in the form of senior management and bureaucracy, but repeatedly with individual participants and place managers in the organization (Punch 1989) (see also ► Chaps. 126, “Researching Among Elites,” and ► 124, “Doing Reflectively Engaged, Face-to-Face Research in Prisons: Contexts and Sensitivities”).

Further, there are some natural barriers between academics and the police that make it difficult for them to work together unless they “negotiate,” “communicate,” and “stand in the other person’s shoes” (Fleming 2010) in order to foster better relations. The first section of this chapter discusses some barriers between academia and policing in more general terms. The second section then focuses on different kinds of police-related research and types of researchers that exist to contextualize how this might affect researcher access to the police organization. The third section discusses challenges involved in researching law enforcement based on my personal experience of conducting two police research projects which had public health

implications. Finally, I draw out some conclusions for the best way forward to foster an ethical and mutually beneficial police – public health research relationship.

3 Unpicking the “Hard-to-Reach” Nature of Police Organizations: Barriers to Police Research

The research relationship between police and academics is fraught with difficulties. Three main barriers are discussed here: differences in subculture; intended aims; trust and communication.

3.1 Cultural Barriers

The police are traditionally a closed, hierarchical organization and very protective of their patch. Relative resistance to research, a closed culture (Punch 1993; Reiner 2000), and the sensitive nature of many of their operations lend itself to a culture of secrecy, making the police a difficult organization to access for outsiders (Kennedy 2015).

Part of the distrust and suspicion is rooted in ignorance of the true purpose and objective of the research and what is perceived to be “academic waffle” and armchair theorizing by academics with no experience of real-life policing. The urgent nature of their daily work means police priorities are shifting constantly and results are demanded instantaneously. The police like solutions that are unambiguous and decisive (Lum et al. 2012; Rojek et al. 2015). On the other hand, the research community would like to be cautious and careful about their conclusions and are comfortable with uncertainty (Strang 2012). The police are constantly accountable to various stakeholders (the public, politicians, and the press) and are rewarded for delivering concrete actions (Rojek et al. 2015). They, thus, value quick and dirty research results that help them achieve their goals. On the other hand, academics are rewarded for scholarly productivity in the form of academic publications. Prestigious publications are dependent on high-quality research of great methodological rigor and conclusions that are the result of slow and reflective deliberation throughout and after the research, and are necessarily a time-consuming process. Thus, not only are the impetus for conducting research divergent between the two communities, but the mismatch of timescales involved also affects research relevance for practitioners (Weisburd and Neyroud 2011).

Academics and researchers, therefore, need to find common research ground to facilitate an entry route, and continued cooperation requires academics to constantly negotiate with gatekeepers and individuals at entry, as well as throughout the research process. The police are aware that researchers need them more than they need researchers to do their work (Engel and Whalen 2010). Hence, it becomes incumbent upon researchers to take that extra step to understand and appreciate police culture and operational pressures and adapt their research aims accordingly to accommodate police expectations without compromising on the integrity of the research process.

3.2 Divergent Aims

For the police, research would be useful only if it is of direct operational or tactical relevance to them. As discussed earlier, results need to be delivered in the short run and in areas that are priority for the organization or senior leaders (Lum et al. 2012). Thus, the police are more likely to be supportive of research that is action and/or policy oriented and helps them achieve their targets. Research, on the other hand, can be purely for the purpose of developing and testing theory (Madensen and Sousa 2015). Both communities might, therefore, hold different views on what kind of knowledge is valuable and worth investing in (Buerger 2010).

Police research can be a “mirror” that reflects the complexities and dilemmas of police operations and processes with the aim of understanding them better; or it could act as a “motor” to impel change and reform in the organization (Innes 2010). Thus, of the two types of research traditions, critical police research and policy police research (Rojek et al. 2015), researchers involved in the latter type of research, are more inclined to work closely with the police to provide theories, ideas, and evidence for the purpose of improving police practice (Bradley and Nixon 2009).

Past experience indicates that often the association between researchers and practitioners can be unidirectional – researchers have been known to just “take” data without actually giving anything useful back in return to the police (Tompson et al. 2017). “Data robbers” are rarely tolerated by the organization and one unhappy experience with such a researcher can “foul the nest” making it difficult for future researchers to access the organization (Punch 1989).

Finally, while the police are sensitive to negative press coverage, academics, on the other hand, are impelled by the need to be transparent and open in disseminating research findings (Tompson et al. 2017). The police would not want any procedural lacunae or policy shortcomings to be highlighted and consequently make them vulnerable to public criticism or their reputation damaged. Conversely, the wider the public discussion of their research, the more beneficial it is for the researchers’ academic reputation. This makes for an uneasy relationship between the two communities since their goals can be divergent.

3.3 Lack of Trust and Cross-Cultural Communication

Some of the subcultural factors and the divergence of goals can be responsible for a lack of trust between police and researchers, unless care is taken to build that trust at the beginning and throughout the research process. The experience of the ‘critical police research’ era has left the police organization suspicious of researchers. Trust can be gained by ensuring that the research is credible and has clear practical applicability, and the resulting policy or operational recommendations are amenable to implementation (Engel and Whalen 2010), especially in the short run. By acknowledging and respecting police tradecraft and individual expertise, as well as the constraints they operate under, researchers can begin to bridge the gap in trust (Stanko 2007; Brown 2015).

One of the main reasons for lack of trust is due to poor communication between police and researchers. Often, it is said communication between the research community and police practitioners is like the “dialogue of the deaf” (MacDonald 1986) with academics being accused of using language that is arcane and inaccessible to practitioners. Failure to regularly report research progress to practitioners can also give rise to suspicion and impact upon trust. Ultimately, police practitioners prefer short, unambiguous reports with clear action directives which will make their job easier (Rojek et al. 2015). On the other hand, academics tend to use language that is cautious and draw conclusions that are more tentative and circumspect than the police would prefer (Madensen and Sousa 2015). Thus, an appropriate communication strategy, where academics have the freedom to disseminate research findings through appropriate academic outputs and also produce reports for practitioners which use simple, succinct, and direct language, becomes essential for engendering trust between the two communities.

4 “Who Is the Researcher” and “What Is Being Researched”? Important Questions in Police Research

The twin pillars supporting a good research project are the credentials (and abilities) of the researcher and the quality of the project itself, judged by its aims and proposed impact. Thus, understanding what kind of research is valued by, and what type of researcher is more acceptable to, the police organization becomes important for any potential researcher.

Police research is of four kinds: research by the police, research for the police, research on the police, and research with the police (Innes 2010). Research “by” the police is conducted by serving police officers or civilian staff and often remains internal to the organization. Much of this research is rarely, if ever, published for external consumption. Research “for” the police is contracted research conducted by academics or think tanks on specific topics commissioned by the funding police organization – this means researchers are given access to those parts of the organization that are of interest to the police. Research “on” the police, their processes and procedures, that possibly involve irregularities (e.g., research on police violence, deviance, abuse, investigations, and soon) are usually topics that are of primary interest to the researcher. Such research usually identifies lacunae and problem areas in policing. The organization can become difficult to access for this kind of research. Conceivably, public health research on topics involving police response to vulnerable individuals or police actions that can contribute to increasing vulnerability, are more likely to be research “on” the police, giving rise to access issues. Finally, research “with” the police is usually conducted in areas that are of policy and operational importance to the police organization and forms part of the larger impetus toward becoming more evidence-based (e.g., research on what works in crime prevention, efficient resource allocation, and so on). They focus on topics that are of interest to, and therefore, more likely to be supported by, the police. Collaborative research, with the police, gets the best results in terms of genuine knowledge

exchange and getting access to aspects of policing otherwise unavailable. Existing examples of successful collaborations of public health-related research done with the police rather than on the police (Reid and Walton 2015) indicates that such projects can be very productive. However, collaboration would presume that the police are equally interested in the research topic and are willing to cooperate not only in terms of giving access, but also possibly by allocating resources.

The challenges involved in getting access to the police have been documented by several researchers (see Reiner and Newburn 2008) and often who the researcher is affects whether and what kind of access they would get. This affects the extent of cooperation a research project is likely to receive from the police organization. Brown (1996) talks about four kinds of researchers, who ally most closely with Innes' different kinds of police research discussed above:

- Inside insiders (research by the police) – internal or in-house research conducted by police officers
- Inside outsiders (research for the police) – professional researchers who work in internal research departments of the police force or professional researchers commissioned by the police to conduct research
- Outside insiders (research on or with the police) – former or retired police officers or staff who become academics and conduct research on the police – (I fall in this category!)
- Outside outsiders (research on the police) – academics or professional researchers who conduct independent research on the police from the outside on behalf of academic institutions or grant funding bodies

The degree of acceptance of researchers by police organizations clearly depends on whether they perceive that the researcher understands policing culture, appreciates the pressures and constraints under which the police operate, and respects practitioner knowledge and experience. Thus, the degree of association a researcher has had with or in the police impacts upon whether they will get easy access to the organization. Further, research reputation and word of mouth testimonials based on previous experience with research have a bearing on whether access will be granted. Whether this access is maintained would depend on the conduct of the researcher and the degree of trust he is able to forge with the practitioners he works with. Whether researchers need in-depth access to and, therefore, greater cooperation from the police would depend on the nature of the research project and research question. It is, therefore, politic for them to consider whether they can move from being total outside outsiders to becoming inside outsiders by co-opting police research priorities for getting greater police cooperation.

Research “on” the police conducted by academic researchers is often the most difficult since there is little reason for the police to grant access. Furthermore, the era of critical research on the police ensured that the police feel under attack or become defensive when they are being researched. Most research on the police, therefore, remains confined to using police data, either open source data or police recorded data which requires minimal police co-operation.

Furthermore, the research approach can either be overt or covert research, or even research that is overt but with covert aims. These approaches carry their own baggage of ethical issues, not only in the initial approach and presentation to gatekeepers and during the conduct of the research, but also whether and how the research outputs will be disseminated, especially if they require approval of the gatekeepers before publication. However, over the years, instances of covert research projects are becoming fewer and further apart given the strong ethics regime that is in place in most reputed universities across the world. Although the aim of my research on use of deadly force was focused on “extrajudicial killings,” I framed it to cover police use of deadly force in all situations, including public order situations and riots. Thus, while the research aim was not covert or deceitful by any standards, its focus on “extrajudicial killings” was not highlighted while negotiating access.

5 Moving from the Personal to the General: Lessons Learnt from Doing Police Research

Other challenges in researching the police include issues of ethics; questions of validity and reliability; informed consent; confidentiality and anonymity; sampling; access, social context, and personal security (Brewer 1990). Drawing from personal experience of conducting several police-related research projects, some of which had retrospective relevance to public health and some with a specific public health angle, there are a few lessons that can be drawn for researchers desirous of conducting LEPH research. In the process of writing this chapter and reflecting on my research projects with the police, I realized retrospectively that most of my police-related research projects had a public health aspect to them, which were never articulated or explored. Researching police violence – shootings of organized criminals (Belur 2010) or in the course of counter terrorism operations (Belur 2013) as well as police responses to domestic violence (Belur 2008; Belur et al. 2014a) – has implications for public health in ways that were not always at the forefront of the research agenda. It was only during the course of conducting research on a multidisciplinary project looking at medicolegal responses to women as victims of burns in India (Belur et al. 2014b; Daruwalla et al. 2014) that the clear implications of the cross over between policing practice and its impact on public health became glaringly obvious.

It is often the case that police researchers are so focused on crime or deviance that they seldom recognize the public health implications of their research. On the other hand, public health researchers tend to focus on violence-related police data and the victims’ perspective and neglect the policing aspect of the problem. Disciplinary expertise can often restrict the overlap of policing studies with public health research. Multidisciplinary studies are recommended but not always possible. My experience of conducting two police research projects on public health-related topics not only reiterated some of the challenges already identified in the literature, but also highlighted some additional nuances of conducting research in countries with a lesser tradition of police research, such as India, where the research was situated. Both projects were qualitative explorations to increase understanding of police

processes and perceptions and involved in-depth interviews with police officers and access to their data. Both of these were researcher-led projects, and involved an “outside insider” approach. As a former Indian police officer, I was an “insider,” but I was researching in police forces that were not the one I served (see also ► [Chaps. 91, “Space, Place, Common Wounds and Boundaries: Insider/Outsider Debates in Research with Black Women and Deaf Women,”](#) and ► [92, “Researcher Positionality in Cross-Cultural and Sensitive Research”](#)). Furthermore, I was conducting the research under the aegis of an independent academic institution and was not in active service, hence brought in an outside perspective. Both research projects were “on” the police – not the most recommended model – but tried to incorporate police participation in some of the decision-making process as explained below.

The first project was on understanding police justifications for use of deadly force in India. The research explored a peculiar feature of Indian policing called *encounters*, which is portrayed as a spontaneous unplanned “shoot-out” between the police and alleged criminals in which the criminal is usually killed, but there are no police injuries (Belur 2010). These killings were suspected to be abuse of deadly force, but it was an open secret that the police carried out these extrajudicial killings of suspected criminals and had a degree of social acceptability and approval (Belur 2009). The criminological study involved conducting in-depth interviews with police officers of various ranks in the city of Mumbai to understand officers’ perceptions and accounts of *encounters* and how they explained, excused, or justified this conduct to themselves and to their various audiences. Officers interviewed had either themselves exercised deadly force, or supervised its use, or facilitated the process and management of the aftermath. It was a highly sensitive topic which required careful negotiation of practical considerations and officer expectations and trust in an ethical manner, while maintaining research integrity and transparency.

The second project was conceived as a multidisciplinary approach to understanding the medicolegal response to women as victims of burns, especially cases of dowry deaths in two cities in India. The research, thus, focused on the response of health professionals and police to women victims of burns. Part of the research was centered exclusively on understanding the police response to women victims of burns, especially in cases of dowry-related burns. In India, special legislation (Section 304B of the Indian Penal Code provides that if the death of a woman is caused by burns or physical injury or occurs in doubtful circumstances within 7 years of her marriage, and there is evidence to show that before her death, she was subjected to cruelty by her husband or his relative for demand of dowry, then the husband or the relative shall be deemed to have caused her death) covers the unnatural death of a woman within 7 years of marriage, as such deaths are suspected to be suicides or homicides resulting from harassment by the husband or in-laws for dowry. Historically, such dowry-related deaths are most commonly associated with burning, usually presented as kitchen accidents. The study involved conducting in-depth interviews with police officers who investigated or supervised investigations of dowry-related burn deaths in the cities of Mumbai and Delhi. This was again a sensitive topic, and involved understanding of the nuances of police investigative and decision-making processes. Given the explicit focus on the public health aspect

of this research meant that the findings were shaped and policy implications were framed and disseminated within a public health perspective (Daruwalla et al. 2014).

I encountered several challenges during the course of conducting these and other projects with the police. Some challenges faced were specific to the context of research in India or the research projects themselves, but others are more common to researching the police organization as such and echo findings in the literature. I focus on the challenges identified earlier which specifically relate to accessing the police for research purposes which may be of relevance for public health research.

5.1 Negotiating Access

Presenting oneself to gatekeepers in police organizations is extremely important when researching a bureaucratic and hierarchical organization like the police since first impressions matter (Warren and Rasmussen 1977). Other researchers have also paid a great deal of attention to how researchers position themselves when approaching senior leaders and individuals within the police organization during the course of the research and the difficulties they had in accessing the organization (see Brunger et al. 2016). Factors such as gender (Huggins and Glebbeek 2003; Belur 2013), status (Reiner 2000), ethnicity, age, and class (Manderson et al. 2006) have an influence on whether and how much access will be granted (see also ► Chap. 92, “Researcher Positionality in Cross-Cultural and Sensitive Research” and ► 126, “Researching Among Elites”). It is important to be aware of this while approaching the police to negotiate access.

My experience was relatively straightforward. I usually got a meeting with senior officers as an ex-senior police officer. However, the experience of getting official permission to conduct research was different during the first study (when I was still a serving officer on study leave) as compared to the second, when I was no longer serving, but was an academic working in a “foreign” university was slightly different. The first project was more sensitive for the police, but I was given unconditional access. In the second case also I received permission, but more hesitantly and there were murmurings about getting permission from the Ministry to allow access to “outsiders.” However, once access was granted, there was complete cooperation. At this stage, presenting the research proposal and its proposed outputs as being beneficial to the organization is very important, even if it is research “on” the police. Personal integrity of the researcher and the institution they represent also matters a great deal at this stage. Unless senior officers are convinced that the research will help the organization or have faith that the researcher will, at the very least, not damage their reputation, chances of success in gaining access are limited.

Further, access negotiation does not end with senior leaders, it has to be renegotiated with each individual during the course of the research. As a hierarchical organization, officers of lower ranks may feel compelled to participate in the research on orders from above, but actually getting them to communicate and answer questions or supply data fully and honestly is a challenge as my experience revealed. Other researchers have found that negotiating this “secondary access” can be quite

difficult (Punch 1989). In my experience, officers would agree to be interviewed, but would either say they did not know the answer or give monosyllabic replies, reducing the interview to mere formality. Although they are unhelpful as sources of data to answer the main research question, such interview experiences nevertheless provide food for thought in terms of – was the interviewee uncooperative because the researcher did not manage to establish trust (and why) or were the nonanswers saying something about the topic or the interviewees themselves that is revealing of the underlying phenomenon. However, in order for researchers to appreciate the nuances of this research, it is important for them to have an in-depth understanding of police subculture and tacit organizational rules in order to overcome some of the cultural barriers identified.

5.2 Agreement on Research Objectives

An effective way of getting cooperation from the police while doing research is to move the focus away from research on the police to research with the police (Innes 2010). However, this implies that both researchers and police practitioners involved have similar priorities and compatible goals and the research output is of practical value to the police. Since both research projects were researcher-led and, therefore, were on topics that interested me personally, it was important to include the aspects of research that might also be of interest to the participating police organization. I took care to spell out the benefits of conducting that piece research for the police in the initial request to access the organization.

I found that police leaders in India had little or no prior experience of research (the Indian police are severely under researched) but were fairly open to giving access based on personal credentials. However, it always helped that the research was framed so that it had practical value for the organization. In order to be more inclusive in setting the research agenda, I always asked whether leaders had any particular aspect of the problem that they would like the research to include. Although I had a methodologically sound sampling framework, I invariably asked the leaders for suggestions on areas and field locations that would be most suitable for the research and whom to interview within those requirements. This was partly to give them the opportunity to contribute to the research but mainly in recognition of their expert knowledge of their area and personnel. To their credit, police leaders were very supportive in suggesting names of officers who had the most experience on the topic or police stations that were particularly prone to the issue under consideration. This more often than not resonated with choices I might have made based on my study of the available evidence.

5.3 Establishing Trust

The police in countries with a history of police research are suspicious of researchers as a legacy of the critical police research tradition era. In countries such as India,

which has been relatively under-researched, the relative lack of exposure to police research, as well as a cultural disposition to maintain secrecy, means that researchers have to establish personal rapport with senior officers and gatekeepers in order to gain their trust. It is again vital at this stage that there is clear understanding regarding what the outputs of the research will be and how it would be fed back to the organization.

However, researching the police has in the past led to uncovering corrupt or deviant practices, consequently straining the ethical boundaries of research protocol (Punch 1989). This indeed places the researcher in a difficult situation while deciding on a response to deviance uncovered during the course of the research. On the one hand, the principles of ethical practice demand that the interests of the interviewee be preserved as much as possible, and on the other, turning a blind eye to deviance can be morally unacceptable. Further, whether the researcher should or should not report corrupt or deviant behavior has implications on the establishment of trust and whether the research project can be successfully completed. My experience of the research on police use of deadly force showed me that officers revealed a number of malpractices, which had serious criminal justice consequences, in faith and trust. I did suffer serious pangs of conscience about potential whistleblowing behavior, if I were to write up the findings. Finally, I resolved the dilemma by protecting my interviewees' identity and criminally incriminating personal information, but at the same time reporting that deviant behavior was occurring and how it was being protected by the organization. This may not have been a morally acceptable path for some researchers, but for the sake of protecting the interests of my interviewees and consolidating a relationship of trust between academic researchers and the police, I decided it was not my place to reveal past misdemeanors. Ultimately, the researcher has to take moral and ethical decisions based on their individual conscience (van Maanen 2008).

An important part of establishing trust is recognizing practitioner knowledge and cultural capital and respecting police processes and operating constraints (Stanko 2007). I encouraged officers to tell me their perspective and was consciously respectful and objective in responding to their opinions. I found that this approach was very useful especially when I was presented with opinions that I would have instinctively disagreed with. Distancing myself from the research and trying to view the problem from the participant's perspective not only made me a more objective researcher, but also enhanced the quality of the research.

5.4 Knowledge Exchange and Dissemination

Knowledge exchange is conceived as a two-way street, with researchers expected to feedback research findings to the police, but at the same time involves learning from practitioners and incorporating their experiential knowledge into the research. Being receptive to practitioner views, carefully observing, listening, asking pertinent objective questions, and understanding police processes and culture (Brown 2015)

are all part of the knowledge exchange agenda and also contribute to building trust and confidence.

As discussed above, the end aims of research for the police and researchers are sometimes divergent. Academics are interested in academic outputs in the form of journal articles or monographs and practitioners are interested in reports that provide them with concise policy and operational suggestions. For researchers to cement an ongoing research relationship with the police, it is important that research findings are communicated to practitioners appropriately at various levels of the organization. Conveying the real-life application of research knowledge to police practitioners has distinct advantages (Fleming 2010) and augurs well for future collaborations.

It is also important that any communication plans are discussed at the initial stages to avoid confusion or misunderstanding once the research is complete. While the police would like to deflect critical media scrutiny, academic communication aims to reach the widest audiences (Fleming 2010). To avoid a conflict, the two communities must negotiate the terms on which research findings will be disseminated at the very beginning and clarify what levels of vetting, if any, the police might have on publication. However, researchers have a duty of care toward their participants and should protect the organization and individuals from suffering adverse publicity or other reputational or professional damage as a result of cooperating with the researcher. This will have a negative impact on future research collaborations and the relationship of trust.

It was my experience that the time lag between the time the research was conducted and when findings were analyzed and finally written up could be from a few months to a few years, especially in the case of ethnographic studies. In that period, officers who had given access to the organization had moved on and there was no follow up on presenting research findings. It was also the case that incumbent officers were not interested in the findings, once they were actually written up. In forces where the link between the police and academic research is not well established, this can often be the case. But, it should be every researcher's endeavor to disseminate headline research findings to the organization that supported the research immediately following completion of the research.

6 Conclusion and Future Directions

It is indisputable that policing has a definite impact on certain aspects of public health protection. Thus, related public health research would benefit from greater access to and better understanding of the policing of a variety of issues including gender-based violence, domestic violence, drug abuse, child and elder abuse as well as treatment of suspects in custody, police violence and police deviance. However, the pursuit of the ideal of collaborative research, or research "with" the police where the researcher and the police work together to achieve a particular aim would be possible mainly in cases where the outcome of the research directly benefits the police in the short run and is of interest to them. Thus, this kind of research requires the two communities to find a research topic that is of mutual interest and a research

question that is of mutual benefit. Personal experience of conducting police research in public health-related topics revealed that, while the starting point of this process can be complicated enough (i.e., finding a research topic and question that is of mutual interest), the process of collaborative research itself can be quite demanding and often unrealistic. It requires building of trust and confidence, understanding of each other's culture, and should be based on open and frequent communication in easily understandable language (Tompson et al. 2017). In reality, most academic research happens to be research "on" the police, strengthening the perception that the police are hard to reach. However, this chapter highlights some steps that a researcher needs to consider when approaching the police for research access. It is important in order to get access to and researching "with" the police collaboratively, research aims should coincide with police priorities and have policy application in the short and medium term. In the current economic and social climate, it is important that there are close ties and cooperation between researchers and practitioners in order for research to retain its intellectual and to have practical and policy implications that are of practical relevance to the police (Innes 2010).

In the days to come, a growing need to support vulnerable populations, especially the mentally ill, provides a strong impetus for greater LEPH cooperation; simultaneously, economic cutbacks and political imperatives for the police to only focus on cutting crime has meant severe withdrawal of police resources for what is perceived to be "social work" by politicians (Punch and James 2016). Given this juxtaposition, there is a greater requirement to adopt an evidence-based approach to understand "what works" as also "what doesn't work" in order to efficiently allocate limited law enforcement resources (Punch and James 2016). Calls for the police to reimagine themselves as "guardians" instead of "warriors" (Rahr and Rice 2015) creates the possibility of a new wave of research to further the guardianship agenda (Wood and Watson 2016). To use the simple example of enhancing the role of police foot patrol, Wood et al. (2015, p. 211) suggest that "the way forward for theory, policy, and practice" for LEPH devises creative ways of dealing with urban vulnerability through multiagency management of "places" instead of "cases," rather than the traditional approach of changing officer attitudes and behavior. There is a call for academics and practitioners in the LEPH field to make a concerted effort "to integrating theories and methods, combined with a cross-system commitment to reducing fragmentation" (Wood and Watson 2016, p. 8). Thus, the future of LEPH research rests in closer cooperation between researchers and practitioners, transcending disciplinary boundaries, sharing knowledge and expertise, and working toward mutually beneficial goals.

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Researching Among Elites

126

Neil Stephens and Rebecca Dimond

Contents

1	Introduction	2198
2	Planning Data Collection	2200
2.1	Ethical Issues and Health Elites	2200
2.2	Sampling and Access	2201
3	Doing Data Collection	2202
3.1	Interviewing Health Elites	2202
3.2	Observing Health Work: The Clinic and Laboratory	2203
3.3	Conferences as Sites for Research Among Health Elites	2205
3.4	The Documentary Cultures of Health Elites	2206
4	Other Health Elites	2206
4.1	Patients as Health Elites	2207
4.2	Social Scientists as Health Elites	2208
4.3	Health Elites as Social Scientists	2208
5	Health Elites as Collaborators: Researching-About, and Researching-With, Health Elites	2209
6	Conclusion and Future Directions	2210
	References	2210

Abstract

Health elites are powerful actors in the medical domain and it is essential that social scientists engage with their work. However, there is a specific set of methodological challenges to conducting this research. This chapter articulates key issues to consider before undertaking research with health elites by drawing

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upon examples from the authors' own research practice. It starts by identifying the ambiguities in defining exactly what constitutes a health elite by drawing upon important literature on the topic. Section 2 discusses ethical issues in health elite research, including providing a sample consent form. It then articulates sampling and access issues with elites, for example, the benefits of purposive and snowball sampling. Section 3 articulates key challenges firstly in interviews and secondly in observational work with health elites (in clinics and laboratories), by stressing the need for flexibility in approach. This is followed by a discussion of conferences as sites for research among health elites, and the resources of elites' documentary cultures. Section 4 reflects upon the increasing significance of patients and social scientists as health elites, and instances of health elites as social scientists. Section 5 considers health elites as collaborators by discussing the rewards and challenges of collaborating with fellow researchers active in generating new knowledge about health. The chapter closes by pointing forward toward the continued need for qualitative social science to engage with health elites, and for researchers to be informed by a methodological awareness of the challenges and rewards of doing so.

Keywords

Elites · Ethnography · Health · Medical sociology · Qualitative methods · STS

1 Introduction

Health research frequently involves contact with, or researching among, individuals in elite positions, and with that comes a set of key issues to reflect upon. Social science research often focuses on the vulnerable in society. The researcher is considered to hold the power in the research relationship, and traditional scholarship on research methods often provides advice for the researcher on the assumption of these power relations. Elite research is less common, although no less important, and requires some reformulation of common ideas in research methodology. Elites in research are associated with the idea of "studying up" and of researching those who are more powerful than the researcher. Where there is power, there are elites, and there is power everywhere. This means that defining exactly what does and does not constitute elite is difficult, and perhaps an unproductive process. We could understand elites as those who are powerful relative to society, in general, or relative to others in their social space, or, as "studying up" implies, relative to the social scientist. Odendahl and Shaw (2002) provide a detailed account of multiple typologies of elites, and show why frequently these do not capture the full diversity. Health elites could be divided into clinical, research, policy, and commercial elites, but it remains likely that this typology too fails to capture important components.

Moving beyond divisions between professional domains, Zuckerman (1996) uses the term "ultra-elite" to describe the most powerful, or revered, among an elite group in her study of Nobel laureates. Payne and Payne (2004) opt for the term "expert witnesses" to describe elites because the term highlights the valuable

contribution to research they can make due to their privileged information, their role as representative of a particular institution or culture, their potential to play a gatekeeping role for others in their group, or their ability to make recommendations for the direction of the project.

However elites are defined, and whether it is because of their public profile or the position they hold in their organization, their elite status in society raises particular issues for the researcher. Research should involve sensitivity to hierarchies in professional settings. In one encounter, Neil Stephens was aware that he was interviewing the director of an organization straight after conducting an interview with an employee. Each party was suspicious about what the other was disclosing in the interview and directly asked Neil to disclose this information. On another occasion, members of an oversight committee refused to take part in an interview, and it was only later that Neil realized it was because they were making staff redundant and did not want this knowledge shared with the researcher or with other staff (Stephens and Dimond 2015a).

When researching among health elites, it can be beneficial to adopt the approach of Aldridge (1993) in his work on Anglican clergy-men and women that stresses the importance of recognizing and making the best of both the differences and commonalities between the researcher and the researched (see also Stephens 2007 for another illustration of this approach). As this chapter will demonstrate, social scientists are themselves in some regard powered and can share common ground with elites in the health sector.

We have conducted nine projects collectively and individually with health elites and we draw on these as case studies to illustrate the points made in this chapter. Rebecca Dimond is a medical sociologist primarily focusing on clinician/patient/family relationships and genetic disease. Neil Stephens is a Science and Technology Studies scholar primarily focusing on innovative biomedical technologies. Both operate with ethnographic and qualitative methods. This chapter uses our work to illustrate key methodological points. It draws upon: (i) Rebecca's study of family/patient/clinician interactions in 22q11 deletion syndrome; a rare genetic disease (Dimond 2014a, b, c), (ii) Rebecca and Neils' interview and observational study of mitochondria disease; a rare disease for which an IVF-based preventative intervention was developed and then legalized in the UK (Dimond 2013, 2015a, b), (iii) Rebecca and Neils' interview and observational study of an anonymous biobank; an institution that holds human biological material for use in biomedical research (Stephens and Dimond, 2015a, b), (iv) Neils' ethnography of the UK Stem Cell Bank; the first institution in the world to hold and regulate national human embryonic stem cell use (Stephens Atkinson and Glasner 2008a, b, 2011, Stephens, Lewis and Atkinson 2013), and (v) Neil's ethnography and interview studies of research active tissue engineers (Stephens 2010, 2013; O'Riordan et al. 2016).

This chapter articulates some of the key issues and challenges in researching among health elites. It focuses on qualitative methods, primarily interviews, and ethnographic or observational work. It is ordered loosely following the format a research project might take. This starts with *planning data collection* (Sect. 2), with subsections on ethics and sampling and access, respectively. Next is

doing data collection (Sect. 3), with subsections on interviewing elites, clinic observations, conferences as research sites, and documentary cultures, respectively. This is followed by other groups who might be considered elite, such as patients and social scientists, and researching-with health elites. The chapter closes with conclusion and future directions (Sect. 6).

2 Planning Data Collection

Research design and methodology are a key part of any research project. This section focuses on some key issues specific to researching among health elites, and complements other chapters in the volume which focus on the more general components of good research practice found in other health research settings.

2.1 Ethical Issues and Health Elites

Most research projects will require ethical approval before carrying out any research. The key element of ethical approval is to ensure the safety of participants, and in health research, this often means ensuring that patients are protected (Stark and Hedgecoe 2010; Israel 2015; see also “Ethics and Research”). Although the “elite” might not appear vulnerable at first, their protection should nonetheless be central in planning any research project.

The elite can be vulnerable in different ways to other respondents. They might be well known, and might feel their public image is at risk if they or their words are represented in a particular way. The most important aspect when researching elites is to be as open as possible about the intentions of the project (and see below for a discussion about the problems and pitfalls of collaborating with elite participants). The consent form template (see Fig. 1) is an example where some issues can be clarified from the start. There are two main aspects which are included here which may not appear on other consent forms:

- Observational notes and interview quotations will generally appear without formal attribution (i.e., anonymously). If I request formal attribution, the research team may identify me if it does not undermine the anonymity of other participants.
- I recognize that the specialist nature of [*respondent specialism*] means some readers may identify me even if interview quotations and observational notes are used without attribution.

Both of these points refer to the fact that because of the unique position held by the elite, anonymization might not be possible.

For research involving cutting edge science, additional issues can be at stake, requiring an extra layer of approval. Some scientists, for example, may be concerned

I, the undersigned, agree to participate in the above project. I understand that:

- Observations are being conducted of my professional practice.
- Observational notes will be written or audio recorded and stored.
- In some instances photographic, audio or video recordings may be made of my professional practice. In these instances I will be made aware and the use of digital materials in the analysis and dissemination of the research will be discussed with [Researcher name] who will respect our agreed position on usage.
- Interviews will be conducted, transcribed and stored.
- The observational notes and interview transcripts may be quoted in academic journals, conference papers, and books, and potentially wider dissemination avenues.
- Observational notes and interview quotations will generally appear without formal attribution (i.e. anonymously). If I request formal attribution the research team may identify me if it does not undermine the anonymity of other participants.
- I recognise that the specialist nature of [respondent specialism] means some readers may identify me even if interview quotations and observational notes are used without attribution.
- My participation is voluntary and I have the right to withdraw from the research process at any time. I can withdraw by informing [Researcher name].

Print name: _____ Signature: _____ Date: _____

Fig. 1 Potential consent statement for interview and observational work with health elites

about disclosure if commercially sensitive information is involved, which has intellectual property implications. This was the case for Neil's research of a tissue engineering laboratory, which was not allowed to begin until he had met with the commercial research office. The result was that Neil was enrolled as a team member, which meant he was not external to the project and thus the participants did not "disclose" information when they shared it with him. Secondly, Neil had to agree to allow the commercial research office to check any reports in advance of dissemination. In practice, no change to Neil's work was required, but without talking to the commercial research office and securing their consent, the research would not have been allowed to take place.

2.2 Sampling and Access

A key aspect of any research project is deciding who you are going to include in your study, a process known as sampling. Researching among health elites poses distinctive sampling benefits and hurdles. Firstly, the elite will generally have a public profile which means a researcher will be able to find the details of those he/she wishes to

invite to participate. Secondly, some individuals, such as the only person in the world who has made a laboratory grown hamburger or the only director of a stem cell bank, are globally unique. It is highly likely, therefore, that sampling will involve a purposive sample where the researcher identifies and makes contact with specific key people rather than random sampling to find respondents who represent a broader group (Liamputtong 2013; Patton 2015; see also “The Nature of Qualitative Research”). This means that a project exploring management strategies of a unique stem cell bank or a rare disease clinic will be able to draw on different sampling strategies than one investigating children’s experiences of going to the doctor, for example.

But elite status also presents hurdles. Blix and Wettergren (2015), in their research with the Swedish judiciary, recognized that gaining and securing access to an elite group involves extensive emotional labor. Although they might have a public profile and appear publically accessible, in practice, making contact can be difficult, and carefully prepared emails, letters, or phone calls might not actually reach their target. It is always worth thinking about the strategy for contact, speak to the elite’s secretary or PA and do not be concerned if you do not receive an immediate reply.

Once contact has been made, or once the research is underway, it is useful to use snowball sampling (Liamputtong 2013; Patton 2015) to make contact with other potential respondents. Your contact can recommend other people in the field to speak to, and might even offer a personal introduction. This approach would mean that the difficulties of making that initial contact can be minimized, but also shows how sampling and access can be deeply entwined practices (see also ► Chap. 5, “Recruitment of Research Participants”).

3 Doing Data Collection

Once ethics, sampling, and access are secured, the fun work of collecting data and being active in health elite social worlds begins. Data can be collected in multiple sites through multiple methods. This section identifies some key research sites and articulates methods issues related to them, including interviewing health elites, observing clinics, labs and conferences, and documentary analysis.

3.1 Interviewing Health Elites

Interviews are one of the most common approaches to researching among health elites. Interviews are relatively easy to organize, and can be conducted either face to face or via telephone or Skype. Stephens (2007) provides a useful exploration of the advantages and disadvantages associated with each method and their practical implications. One of the advantages of course is that telephone/Skype interviews are cheaper to conduct than face-to-face interviews, which can be an important consideration for a project with limited resources and where the elite in a particular field are based in different countries.

Elite interviewing can raise particular challenges in addition to the general expectations about the role of the researcher when conducting interviews. Our first key message is for the researcher to appear professional and be flexible (Harvey 2011). Arrive early for interviews, and dress according to the space. Morrissey (1970) stresses the need for flexible timetabling to respond to elites' busy diaries, and the potential for interviews to be cut short or be interrupted. It is worth clarifying at the start how much time they can afford, and be prepared to sit and wait while your interviewee takes a phone call or goes out to meet a patient or colleague. The second key message is to prepare for the interview. There is a growing amount of literature on elite interviewing, which frequently stress the specific nature of the elite interview, particularly around power. Ostrander (1993) argues the social scientist should use nonverbal cues and direct questioning to assume a dominant position during interviews. Cassell (1988), Dexter (1970), and Hunter (1993) stress preparing for gate-keeping questions through which the interviewee tests the caliber of the interviewer. Petkov and Kaoullas (2016) suggest using an intermediary who can help a researcher establish trust with the respondent and would be able to intervene if the respondent is "deliberately or unintentionally withholding information" (p. 1). Elites are typically highly engaged in the interview topic and capable of discussing detailed points at length, but they might not agree to take part in a research project if they feel that it would be a waste of their time. Once again, preparation is key – which means potentially learning about both the topic and your participant. One issue is whether the researcher needs what Collins and Evans (2007) call "interactional expertise," that is, the ability to speak the technical language of the expert being interviewed. Mikecz (2012, p. 482) highlights the importance of gaining rapport, claiming "the success of interviewing elites hinges on the researcher's knowledgeability of the interviewee's life history and background."

Although interviewing elites can appear daunting at first, in our experiences, interviews often work very well, are relatively easy to conduct, and frequently are enjoyable and informative encounters. Out of more than a 100 elite interviews conducted by Neil, only one could be described as going badly – in that the interviewee seemed reluctant to engage in the spirit of the interview – yet even this interview produced excellent data. Particularly in the health field, the elite are often aware of the value of evidence-based research and that their participation can contribute to this knowledge culture. We have found that once a slot in their diary has been arranged, health elites are typically affable, articulate, and keen to contribute. Indeed, although some interviews have been cut short, more often than not our participants have been able and willing to rearrange their diaries in order to extend the interview, in extreme instances with interviews lasting 3, 4, or 5 hours. Our final message about interviewing elites is about engaging the participant so that they see the merit in the research and enjoy the opportunity to reflect upon their professional role, activities, and personal perspectives.

3.2 Observing Health Work: The Clinic and Laboratory

The clinic is possibly the first site that health researchers think about when undertaking observational research, as the consultation exemplifies the

relationship between health professional and patient. Likewise, when thinking about the work of scientists, most people would think about the laboratory. The power of the health professional or the scientist has been a key theme within the sociology of work and the hierarchy of the clinic and laboratory can, therefore, have important implications for the researcher. Here, we discuss the important role of a gatekeeper, and the tension between wanting to observe mundane everyday work compared with the expectation that research will focus on the extraordinary.

Gaining access to the clinic or laboratory will often depend on forging a good relationship with its director, and this person will then act as an important gatekeeper for the research. One obvious example is that the clinician is in a position to tell the researcher when and where meetings will take place, and can help set up access, e.g., informing the receptionist to expect the researcher to attend. But, it also means that, to a large extent, the researcher can become wholly dependent on the gatekeeper, which might lead to limited access if he or she does not understand or recognize the value of social science research.

There might also be confusion about the role of the ethnographer. Ethnographic work requires attentiveness to the mundane and everyday activity conducted in a given site (see also ► [“Ethnographic Method”](#)). Yet, it might be assumed by clinic or laboratory staff that the researcher wants to observe specific and special “events.” Within a medical space, routine tasks such as team meetings, chats over coffee, or training students might not seem like important “work” and appear mundane to those performing them. But, these activities are rich in detail for the ethnographer (Atkinson 2015). Thus, once access is secured, the researcher might still need to engage in a process of negotiation about what to witness, why, and when. The problem, of course, is that health professionals will no doubt be busy and in-depth conversations about the aims and philosophy of the research are not their top priorities.

The health professional as gatekeeper situation might also mean that the researcher witnesses events far beyond what was envisioned in the planning of the project. For example, on one occasion, Rebecca arrived at a clinic to interview the director, but was instead led into a “viewing” room, where along with a technician, speech therapist, and father, she watched a consultation with a 6-year-old girl and her mother through a one-way window. Rebecca had not been introduced to anyone in the room, but as they were all watching the consultation proceed, she felt unable to explain her presence or ask for their consent. Indeed, at the direction of the clinician, it is possible that many of those who fall under the researcher’s gaze, including patients, parents, medical students, receptionists, and members of the clinic team, are not always explicitly informed about their presence. On many occasions such as this, the researcher might feel like a “guest” in someone else’s busy work environment and, therefore, relatively powerless to influence proceedings.

It is possible that the key contact will act as a gatekeeper throughout the time when the researcher is observing. It might be the clinician who identifies which

patients to observe and it can also be the clinician who decides when note taking is appropriate, even though this might be specifically included as a tick box on the consent form. Indeed, a researcher might be directed in many other ways by a clinician; for example, it is not unusual to be asked to take charge of children during a consultation or to go to the waiting room to call in the next patient. These occasions blur the boundaries of whether the researcher is a participant in the event or a nonparticipant observer. Whatever the task, demonstrating a willingness to get involved might be important for securing future collaboration, as long as it does not ultimately compromise the research.

3.3 Conferences as Sites for Research Among Health Elites

Conferences are very useful sites for a researcher. First of all, they offer an introduction to the field, a chance to see what kinds of information are exchanged, who are the elite (for example, who acts as host or chair but also who are mentioned as success stories), and how individuals relate to each other (Dimond, Bartlett and Lewis 2015; González-Santos and Dimond 2015). One of the advantages of going to a conference is that the researcher will have a wide opportunity to interact with others, and fortunately this means many opportunities for meeting “the elite.” In addition, conferences blur the boundaries of informal and formal working practices, and subsequently you might talk to the person sitting next to you during a session, or have a chat and hear gossip over lunch or at a wine reception. Collins (2004) argues these informal opportunities could be even more important than attending the formal presentation sessions. It means that when you go to a conference, do not just focus on attending the presentations but look around, identify key people in the field, and seek out opportunities to engage with them.

One of the advantages of observing conferences is that it is easy for a researcher to make notes. Note taking is an essential part of the ethnographer’s tool box, but as with any site, decisions have to be made as to when and how notes are made. Fortunately, the conference provides a natural stage for recording events – welcome packs contain a logoed pen and notepad and the physical location, and rows of chairs facing forward emphasize the conferences as a site of learning. But, the occasions when an ethnographer takes notes might not correspond with the “norms” of the event. This was the case at a parent-led conference when Rebecca realized that no one else around her was writing. Although many attendees, who were mostly parents, held a pen in their hands, they would only jot down an email or website, the details of a medical contact, or the name of a treatment. On another occasion, at a scientific conference, it was the timing of note taking that attracted attention. Rebecca noticed that those sitting around her only made notes during particular presentations. In contrast, Rebecca wanted to take notes through the entire day and this meant during the welcome address, the speaker introductions, and the question and answer sessions. Being visible as a researcher is not a problem, but it means that the researcher needs to think about “impression management” (Hammersley and Atkinson 2007), which includes deciding what to say to others about the research, what to wear, and how to behave.

3.4 The Documentary Cultures of Health Elites

An advantage of researching elites is that it is likely that researchers will be able to access publically available information about the participants and their work. Documentary evidence can be used in combination with other research methods, for example, to help with the preparation for an interview. But, documents also represent a textual footprint that can be used as research data. Prior (2003) highlights how what counts as a “document” is wide ranging, including videos, diaries, paintings, and photographs, all of which can produce a rich insight into a social world (see also ► “Unobtrusive Methods”).

The example of the value of documents as data given here is based on the mitochondrial donation project. This germ-line technology required a change in the UK law for it to be offered to patients, and this involved a lengthy process of consultations and reports. There were several parliamentary debates which were transcribed and available online. There were also four scientific reviews and several public consultations all of which resulted in publically accessible reports. Some of the evidence submitted by patients, professionals, and publics were also publically accessible. As the legalization of mitochondrial donation was controversial, it also attracted extensive media coverage. Media interest in the techniques involved attention grabbing headlines and overviews of new developments, but what was interesting in the mitochondria debates was that the media was also used by key people in the field as a way of declaring their personal or professional perspectives. Letters were published by high profile individuals or groups; for example, one letter included signatures from five Nobel Prize winners, and another was signed by 40 scientists from 14 different countries. Those directly involved in developing the techniques or were members of oversight committees also published sometimes lengthy opinion pieces. Thus, media at a particular time could be used not just to identify key people in the field but also to explore their public accounts.

The wealth of publically available documents, particularly around a controversial or current debate, can enable researchers to conduct research by accessing information about the activities of elite health professionals. But, the researcher is reliant on the reports being made public, and this is clearly not the case at all times. Openness depends on institutional requirements, culture, and national legislation. In the UK, the law now makes it possible to access information through a Freedom of Information request. This might produce documents which have not been made publically accessible and might reveal different insights or new perspectives.

4 Other Health Elites

The first thoughts that come to mind for many when they think of health elites are professionals: clinicians, scientists, and policy-makers. However, when thinking about the specific methodological issues raised when researching health elite, it is useful to recognize other groups who might be considered, or might consider themselves, as elites.

4.1 Patients as Health Elites

It is productive to categorize some patients as a type of health elite. These are patients engaged in the politics and practice of managing the healthcare of other patients beyond their own, either through, or in conflict with, mainstream health institutions. They typically fall somewhere between patient advocacy and patient representation.

A classic study on patients as both experts and political activists is Epstein's (1996) work on HIV activism and the credibility struggles they engaged in to challenge and reconfigure mainstream scientific opinion in the field. Kent (2003) provides a related example of confrontational patient activism about lay experts and the politics of breast cancer. These are important sites of research, but patient elites are also evident in contexts less antagonistic to mainstream health policy, and can be embedded within the routine operation of healthcare practice.

The mitochondrial donation policy debate featured two related types of patient elites. The first – the Lily Foundation – is a voluntary patient-run patient advocacy group that delivered a powerful voice on behalf of families with mitochondrial disease. The second – Muscular Dystrophy UK – provides advocacy and support for, by, and on behalf of, people with muscular dystrophy through the professionalization of patient representation.

The illustrative case studies on biobanks also involved patient elites in the form of “lay board members” or “patient representatives” on oversight committees (Roth 2011; Mallik 1997). They contribute to discussions about an institution's day-to-day policy and long-term plans, in some instances even being party to decisions to shut institutions down (Stephens and Dimond 2015a; see also Stephens et al. 2008). Some “lay” members feature on multiple oversight boards and make a significant time commitment to decision-making roles. Of course, the term “lay expert” is problematic, as their expertise is not “lay” but unaccredited through formal qualifications (Collins and Evans 2007). Methodologically, the term also points to the hybridity of their status, suggesting a form of “non-elite elites.” These are not institute directors or Nobel Prize winners, so their type of eliteness requires consideration.

We can understand people in these positions as patient elites in at least three complementary ways. Firstly, they are elites within their own communities, adopting a position of representation of the voice of others, thus giving them power within their communities and access to other professional power elites. Secondly, they are elites in that their work – in policy debates and on oversight committees – is the work of powered people, patients or not. And thirdly, while we cannot generalize from our own projects, some people in this position transpose elite professional experiences from other domains into their patient advocacy work, deploying the education and cultural capital developed elsewhere into the health field. This said, they are not traditional elites as their patient-ness situates them differently to professionalized power, so we advise remembering the hybridity of the “lay expert” and the importance of being reflexive about research relationships when “studying up” with patient elites.

4.2 Social Scientists as Health Elites

Social science has become an important component of health practice, and as such social scientists often hold elite positions in health settings. The case studies included interviews with bioethicists, lawyers, sociologists, and anthropologists about their work in shaping health and biomedical policy and practice. Health economists and political scientists are just some of the other social science elites that can be encountered. Interviewing people who properly understand the theoretical frameworks that you work with, and maybe have read (or peer reviewed) your papers, can be both enjoyable and challenging. Interviews with participants who closely share your disciplinary perspective sometimes feel entwined with a sense of shifting between knowing and puzzlement as the interviewee recognizes, or tries to recognize, the ideas underpinning your line of questioning. They can also sometimes spontaneously begin reflexive analysis of their own accounts, articulating how their previous utterance might be understood by Foucault, or Latour, or Goffman. This is about establishing rapport as a reflexive operation; both interviewer and interviewee contributing to the smooth running of the interview. It is also about negotiating elite status, and the status similarities and differences between interviewee and interviewer.

While the intrasocial science elite interview may be framed by its intrasocial science form, we do not believe this invalidates or undermines the data collected. This is for two reasons. Firstly, in analysis, it is simply dealt with, recognized, and understood reflexively for the situated account that it is. All interviews are situated, and this is just a distinctive form of that situatedness. Secondly, social science is an important component of contemporary biomedicine and that should not be written out of the account but accommodated within it by acknowledging its role. During Neil's ethnography of the UK Stem Cell Bank, he and fellow social scientists sometimes joked that there were more social scientists that had conducted interviews at the Bank than there were stem cell lines in the Bank itself. Numerically the joke was true, and the humor hinted at an over-supply of social scientists in the field, but actually this should be understood as an indication of the role of social science in biomedicine and should be treated as a topic to research as opposed to an embarrassment to be written out. The same can be true of observational work. In one encounter, Neil stood in a line of three ethnographers all writing fieldnotes about the practices they were observing. He ensured his fieldnotes recorded this fact, as it was an important interaction to analyze. Social science can be constitutive of biomedical and healthcare practice, and we should deal with it reflexively as a resource to improve our analysis.

4.3 Health Elites as Social Scientists

Finally, as well as social scientists becoming health elites, progressively health elites are becoming social scientists, in that medically trained professionals are more and more involved in studying and conducting social research. Neither of us are health

elites in this traditional sense, so we are not in a position to draw upon our own experience on being, for example, a medical consultant interviewing other medical consultants. However, work has been published on these relationships, and we direct the reader toward Luam and Sima (2006) for an account.

5 Health Elites as Collaborators: Researching-About, and Researching-With, Health Elites

Social scientists and health elites share a number of professional activities. Shared institutional and cultural foci can include conferences, publications, public engagement interests, and the demand for securing research funding. Together, these can facilitate researching-with, in addition to researching-about, health elites. Examples include copresented talks, coauthored publications, coinvestigator research applications, and coordinated public engagement activities. In the health research sector, this researching-with is typically distinctive to researching among elites, as their elite status is part-premised in the professional cultures that are shared.

Coauthoring or copresenting with health elites brings both challenges and opportunities. It can allow fruitful exchange and mutual learning between coauthors. It can also allow social science research to reach wider audiences and results in a valuable output on end-of-award reports. But, it does require attention to both voice and messaging as the text works to unify divergent interests, methods, and world views. One of our examples (see Stacey and Stephens 2012) takes the unusual step of decoupling the voices by featuring alternating sections from the authors detailing their experience of participating in health elite research.

Similar tensions run through applying for and conducting interdisciplinary research. Joint projects vary from those in which the disciplines are distinct but in parallel (perhaps through a work-package structure) to those in which disciplines genuinely intermingle their practices and outputs; a distinction that Lewis and Bartlett (2013) term individual and collective interdisciplinarity. When researching-with health elites, a full realization of the latter could be a collaborative ethnography in which the participants are active in designing research questions, analysis, and publishing (Lassiter 2005), or a health-based intervention project in which the social science directly impacts upon patient outcomes.

In all of these contexts, the social scientist must be attentive to the power relations active in researching-with health elites and how their own contribution is situated in relation to the groups they study. Researchers should be reflexive about the relationship between critique and legitimacy when entering into researching-with arrangements. Does researching-with undermine the critical capacity of the work? Does researching-with operate to lend legitimacy to the fields being studied? How is the social science research situated within the broader political economy of health? We do not believe there are simple (or indeed right or wrong) answers to these questions. But, we urge the social scientist to be aware of the potential and operate reflexively in doing so.

6 Conclusion and Future Directions

In this chapter, we have highlighted the difficulty of identifying what or who counts as elite. But, whether this includes all or some health professionals, scientists, policy makers, expert patients, and even social scientists, it is clear that research involving the elite creates particular challenges for the researcher. As we have discussed, the elite might have a public profile, which makes them potentially easy to identify, but there are also drawbacks. Being involved in a research project, where they might not be fully in control of the output, might be seen as a risky strategy. We can also assume that elites are particularly busy professionals, which places additional burdens on researchers to be flexible with timing, and be ready to grab opportunities for contact wherever possible. But, we also recognize, that as the experts in their field, they are also highly engaged. If the researcher gets it right, and prepares for the interview or observation, then the elite can be agreeable, supportive, and above all, interested in progressing the research. Thus, despite the challenges, the benefits of researching elite, and potentially being helped to produce good research, make the endeavor worthwhile.

Looking forward, the future for qualitative research with health elites is both demanding and rewarding. Novel medical technologies and new organizational and interactional forms in healthcare mean the ongoing succession of new research topics in health will continue. Innovative technologies arise from the laboratories and the increasing complexity of the globalized world means new socioeconomic contexts give rise to uncertainties that will require exploration. What we can be sure about is that, in many cases, these novel situations will have health elite involvement, and it is important there are social scientists there to analyze what happens.

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Eliciting Expert Practitioner Knowledge Through Pedagogy and Infographics

127

Robert H. Campbell

Contents

1	Introduction	2214
2	Domain-Specific Definitions of Expertise	2214
3	Estimating the Correct Number of Interview Candidates	2216
4	Learning-Based Knowledge Elicitation	2216
5	Cognitive Dissonance Theory	2218
6	Conducting the Research Interviews	2219
7	What the Findings Tell Us	2221
8	Conclusion and Future Direction	2222
	References	2223

Abstract

Qualitative research routinely requires expert practitioner knowledge to be elicited. However, effectively eliciting tacit or implicit knowledge can be problematic. This chapter presents a method in which pedagogy and infographics were combined to elicit the knowledge of expert professionals. During interlocations, using a progressive series of infographics accompanied by explanations, research participants were quickly taught new topics. Then as the learning occurred, they were asked to reflect on their experience using their new knowledge as a lens. Deployed with Information Systems practitioners, the approach was effective, bringing forth 130,000 words of relevant and advanced discourse. Although details of the Information Systems research are presented in the chapter as an illustration, the chapter's foci are the method's underpinning principles and deployment. It is believed that this approach could be easily transferred into a range of qualitative research domains. Given the ambiguity

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surrounding the term, the concepts of expert and expertise are also discussed along with the challenge of establishing definitions for a given domain.

Keywords

Expert · Expertise · Expert knowledge elicitation · Pedagogy · Infographics · Information systems practitioners · Information systems research · Qualitative research

1 Introduction

Expert knowledge elicitation, although difficult (Kidd 1987), is a proven empirical technique exploited in a range of disciplines (Hoffman et al. 1995). This chapter presents a method in which knowledge was elicited from expert Information Systems (IS) practitioners on the acceptance of new computer systems. A method that, it is proposed, could easily be adapted for deployment in other domains.

Based on a defensible epistemic assumption that significant understanding and good practice can be found in the knowledge and competencies of expert practitioners, the challenge was to interact with experts in a manner that went beyond superficial conversation, and would in addition to their explicit understanding, elicit their implicit and tacit knowledge. What Leonard and Swap (2005) describe as the special forms of “experience-based expertise” or the “deep smarts” that define an expert. This was achieved through pedagogy and a type of graphic known as an infographic. Accordingly, this chapter pursues three major themes: the challenge of defining expertise; pedagogy as a route to knowledge elicitation and the use of infographics in this process; and for illustration purposes, the Information Systems (IS) research for which this method was originally developed.

This chapter discusses my own experience of research that involved the elicitation of knowledge (on the acceptance of new computer systems) among Information Systems practitioners. The chapter opens with a discussion on expertise and the difficulty of defining experts in a given domain. A short section then considers how many experts need to be interviewed in research of this type. The theory behind the pedagogy-based approach by which knowledge was elicited is then addressed before a description of the interviews themselves. Finally, the effectiveness of the approach is reviewed along with suggestions for future work.

2 Domain-Specific Definitions of Expertise

Although expert knowledge elicitation is an established empirical technique (Hoffman et al. 1995), there is no agreed definition of an “expert” or “expertise” that spans all subject matters (Hoffman et al. 1995; Gobet and Campitelli 2007; Germain and Ruiz 2009). The only real cross domain consensus is that expertise constitutes a blend of domain specific knowledge, skills, and experience (Germain and Ruiz

2009). Qualifying criteria are topic dependent (e.g. Germain 2006). Accordingly, a reasonable place to start any expert interview-based research is to acquire or construct a relevant definition of expert.

Definitively defining expertise in any given subject could prove to be a significant research venture in its own right (Germain 2006; Gobet and Campitelli 2007), but this is not normally necessary. In most cases, all that is required is a definition adequate for candidate selection. Hoffman et al. (1995) surveyed definitions of “expert” and proposed a return to craft guilds terminology. It is a significant observation that, failing to find clear definitions in modern literature, they opted to revive a Middle Ages description. Accordingly, Hoffman et al. present a taxonomy with seven respective categories: naivette, novice, initiate, apprentice, journeyman, expert, and master. At one end of this comprehensive spectrum is the naivette “who is totally ignorant of a domain” (p. 132) with masters being those who are the expert in a subdomain, “whose judgements set the regulations, standards or ideals” (p. 132). Most relevant, however, is their definition of an expert:

The distinguished or brilliant journeyman, highly regarded by peers, whose judgements are uncommonly accurate and reliable, whose performance shows consummate skill and economy of effort, and who can deal effectively with rare or “tough” cases. Also expert is one who has special skills or knowledge derived from extensive experience with sub domains. (p. 132)

The focus of the IS research in which this method was deployed was the user acceptance of new computer systems. Interview candidates needed to be experts in this field, and unsurprisingly, there was no existing definition. Accordingly, based on the Hoffman et al. (1995) definition, the following was constructed.

IS implementation experts:

- Are highly regarded by their peer group and referred to using distinguishing terminology such as leader, expert, best, or strongest
- Have practitioner experience in excess of 8 years
- Have led the implementation of least three major systems and have participated in many more
- Have a proven track record of dealing effectively with “tough” situations

The numerical values contained in this definition came from my own experience of corporate recruitment, in which minimal experience requirements were set for those entering senior positions. For more general fields of expertise, the criteria set by professional bodies could be of assistance. It is not claimed that this definition is definitive but it was adequate. It was also, for verification purposes, exposed to a selection of practitioners in the field who confirmed it to be a reasonable definition. Participants who met these criteria were then selected from a range of sectors and organizations.

A common belief sometimes even quoted on popular television (e.g., BBC 2015) is that 10,000 h of practice produces an expert, regardless of the individual, practice, or domain. Given its prominence, this merits a special mention. Popularized by the

best-selling book “Outliers” (Gladwell 2008), the “10,000-Hour Rule” (Gladwell 2008) is perhaps best described as a misrepresentative simplification of Ericsson et al. (1993). Although not without merit, no credible academic literature supports this simplistic definition.

3 Estimating the Correct Number of Interview Candidates

Estimating the correct number of purposively sampled participants is also known to be problematic (Guest et al. 2006; Onwuegbuzie and Leech 2007). For qualitative research, general guidance is that data gathering should continue until saturation has been reached (Onwuegbuzie and Leech 2007; Liamputtong 2013; see also ► Chap. 63, “Mind Maps in Qualitative Research”). Reviewing use of the common term “theoretical saturation,” Guest et al. (2006) found that although this was routinely proposed as a milestone for establishing a sample size, the same literature “did a poor job of operationalizing the concept of saturation, providing no description of how saturation might be determined and no practical guidelines for estimating sample sizes for purposively sampled interviews” (p. 60). They go on to review work where interview numbers are suggested, exposing an erratic set of figures. Although many papers suggest small numbers (perhaps only five or six participants) often to be adequate (Guest et al. 2006), it has to be concluded that no one can say how many interviews are enough.

In my research, the interviews were long (about 90 min) and being conducted “expert to expert” were intensive and productive. After a pilot interview, it was thus estimated that saturation would be reached quite quickly. Accordingly, 23 candidates were originally identified, 19 approached, and then only 15 were interviewed. All were convenience sampled from my personal network. On reflection, just the eight strongest interviews would have been sufficient, but it took all of the interviews to identify those eight. Debatably, the final three also need not have occurred as no new major themes emerged. They did, however, serve as an assurance that saturation had occurred and provided additional supporting examples.

4 Learning-Based Knowledge Elicitation

This method is based on the epistemic assumption that significant understanding and good practice can be found in the knowledge and competencies of expert practitioners. Modeling this on the famous four stages of competence model (see Fig. 1), it could be said that expert practitioners have significant unconscious and conscious competence that causes them to recognize, understand, and manage phenomena. Making the same observation through Kolbs (1984) experimental learning theory (see Fig. 2), it could be said that expert practitioners have concrete experience that they may or may not have reflected on or conceptualized.

In my research, the intention was to use learning as a vehicle by which participants would come to reflectively observe and/or abstractly conceptualize their

Fig. 1 The four stages of competence

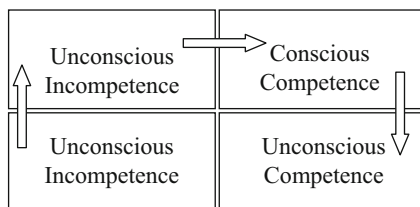
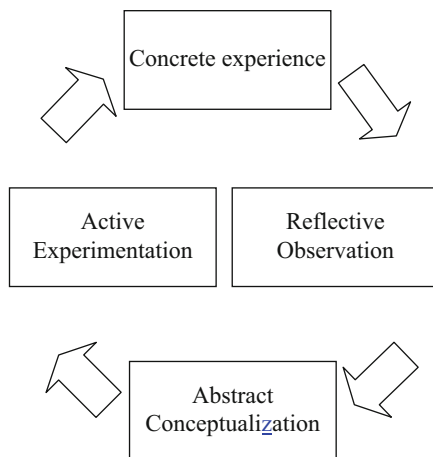


Fig. 2 Kolb's experimental learning cycle (After Kolb 1984)



concrete experience. Specifically in this case, the focus was user attitudes during IS implementations. Accordingly, participants were taught notions of attitude change from social and cognitive psychology. As the learning occurred, they were then encouraged to reflect on their experience using this new knowledge as a lens.

The learning was assisted by infographics. Infographics are diagrams (and other graphics) specifically developed to portray information. A famous example is the London Underground map. Infographics seek to provide simple access to just the information that people need for the time that they need it. They need not be memorable, entertaining, or artistic. In the London underground example, information is particularly fleeting and superficial, passengers ignore the complexity of an underground rail system, extracting from the graphic just the information they need at that moment (i.e., which train on which platform).

Participants were provided with a progressive series of infographics accompanied by explanations and guidance that incrementally built their understanding of the relevant theory, sufficient to invoke reflective observation and abstract conceptualization. Their understanding of the theory was neither deep and durable nor precise, but it was adequate. As each interview proceeded, new infographics supported by dialogue incrementally provided additional new knowledge. Then, as the participants learned, they were encouraged to reflect on their practice using their new knowledge as a lens; considering where related phenomena had occurred, the

impact, cause, and management responses. The dialogue was then audio recorded and transcribed. In this case, the transcribed data was subjected to a thematic analysis (Braun and Clark 2006; Liamputtong 2013; see also ► Chap. 48, “Thematic Analysis”).

5 Cognitive Dissonance Theory

The attitude change theories used in this case were Cognitive Dissonance (Festinger 1957), the Elaboration Likelihood Model (Petty and Cacioppo 1986), and an amalgamation of those that have evolved from Tajfel’s Social Identity Theory (Tajfel and Turner 1979). Before going onto discuss the interviews, this section introduces Cognitive Dissonance Theory by way of example.

At its most basic, Cognitive Dissonance Theory proposes that people are inclined to change behaviors and attitudes to ensure consistency with belief, values, and perceptions. Failure to acknowledge this consistency of perception causes dissonance. Festinger, and some of those who followed him (e.g., Sakai 1999), actually created formulae to define its impact and scale. The greater the dissonance the greater the motivation to resolve it and the probability of change. Should dissonance be caused by contrasting attitudes, change usually involves weaker attitudes giving way to the stronger. Since the late 1960s, researchers have attempted to understand what motivates dissonance, and three dominant revisions have been proposed with supporting evidence (Harmon-Jones and Harmon-Jones 2007), namely, Self-Consistency Theory (Aronson 1968, 1999), Self-Affirmation Theory (Steel 1988), and “A New Look at Dissonance Theory” sometimes called Aversive Consequences (Cooper and Fazio 1984):

- Self-Consistency Theory proposes that the self concept (or a violation thereof) is the primary cause of dissonance; people suffer dissonance if they compromise their own self-image.
- Self-Affirmation Theory proposes that people uphold a set of values and thus maintain an overall self-image. Simon et al. (1995) performed significant interpretive work and found that when suffering dissonance, if an individual confirms a value (any value, relevant, or otherwise), then attitude change does not occur, they are effectively distracted from the dissonance and its effect is subdued. The Self-Affirmation premise is that dissonance is caused by the disruption of the holistic self-image, if something then confirms the self-image (anything), consistency is restored.
- A New Look at Dissonance Theory was published after Cooper and Fazio (1984) repeated some of Festinger’s original experiments and concluded that dissonance is invoked when an individual feels responsible for possible adverse consequences. When people were paid substantially to tell a lie, they avoided dissonance because the perpetrator of the bribe is the originator but, when the pay is low, the subject has no one else to blame and becomes dissonant.

An early experiment (Aronson and Mills 1959) compared the experiences of women who had undergone an initiation to join a group; some had undergone a severe initiation while others had undergone a mild initiation. Those who underwent the severe initiation were subsequently found to value group membership more. The discomfort of the initiation had invoked dissonance forming attitudes that valued group membership. This is a notion that is now well established and employed for various purposes (e.g., Wicklund and Brehm 1976; Axsom and Cooper 1985; Beauvois and Joule 1996; Draycott and Dabbs 1998). An extreme witness to this would be gang initiations. In another example, Festinger and Carlsmith (1959) paid people to lie, claiming that a tedious task was interesting. When the fee was high, people did not experience dissonance (they did it for the money and felt fine), but when the fee was low, there was significant dissonance. Unable to justify their lies, their attitudes about the job changed and the proclamations thus ceased to be lies and became genuine representations of belief. This can all be aligned with Brehm's (1956) findings that cognitive dissonance is greater when a choice is hard. It stands to reason: if multiple options appeal then choosing can be difficult; conversely, if given the choice between something pleasant and something horrible, the choice is simple.

As well as providing an introduction to cognitive dissonance this section intends to provide some idea of this theory's complexity. The other two attitude change theories employed are equally complex. However, the intention was not that participants should truly understand cognitive dissonance, only that they should learn it a to level where "reflective observation" and "abstract conceptualization" are invoked and it could serve as a lens for reflection on their experience.

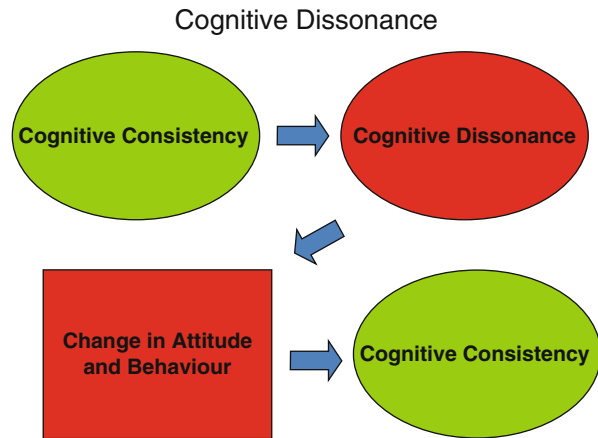
6 Conducting the Research Interviews

In my research, each interview began with a confidentiality statement confirming that no information would be published that might enable the participant or any other actor discussed to be identified. Given the nature of the organizations involved, this guarantee was necessary for a significant "warts and all" corpus to be gathered. Given the importance of interviewee comfort (Hair et al. 2000; Babbie 2016), interview locations were decided by participants and accordingly ranged from private offices, to board rooms, coffee shops, and people's homes. Participants were also given breaks as required and in one case the interview was concluded on another day. Once the introductions were complete, participants were shown a simple graphic (see Fig. 3) on an A4 laminated sheet. It might be observed that this is a simple illustration, comparable to what a teacher might quickly draw on a pen board during class.

A simple accompanying explanation was then provided. In each case, it was ad-libbed but went something like this:

Cognitive dissonance refers to any uncomfortable mental state that could cause attitudes or behaviors to change. For example, anger, disappointment, embarrassment, confusion, shock,

Fig. 3 Infographic used to introduce the concept of cognitive dissonance



moral dilemma and so forth. It is a generic term for uncomfortable cognitive experiences that cause one to reconsider.

As an example, consider a parent who suddenly discovers that an activity is hurting their child. On the diagram, the parent would start in the first green oval “cognitive consistency.” Unaware that they are harming their child, their thoughts are consistent and comfortable. Then when they discover that “cake for breakfast everyday” is bad for their child they enter the red uncomfortable area “cognitive dissonance.” To get out of this discomfort they need to change their attitudes or behaviors, taking them into the red square. Perhaps their attitude toward cake may change and as a result, they might start to provide something healthier for breakfast, or their attitude toward the source of the information may change causing them to conclude that it is invalid. Either way, with an attitude change complete and perhaps also a change in behavior, they are returned to the comfortable state of cognitive consistency.

Participants were then asked if they felt they had a basic understanding of what cognitive dissonance was. In most cases, they did but if necessary, further clarification and illustrations were provided. They were then guided to reflect on their experiences of cognitive dissonance among users during IS implementations, how it became manifest, its cause, effect, how it was managed and good practice that emerged. In particular, they were encouraged to reflect on real experiences and not imagined scenarios as this is understood to produce more accurate and reliable information (Ericsson and Simon 1993; Cote et al. 2005). As participants concluded a reflection, they were asked if there were any more occasions they could think of. For some participants, this basic understanding of cognitive dissonance kept them reflecting for some time where as others needed additional stimuli after only a few minutes. Accordingly, as required to keep each participant reflecting and conceptualizing, more advanced cognitive dissonance related theory was gradually introduced using additional graphics and explanations. This continued until a substantial amount of discourse had been elicited or it was apparent that no more would be

forthcoming. The same process was then undertaken for the second and third attitude change theories.

7 What the Findings Tell Us

This method was effective in eliciting expert knowledge. During the 15 interviews, 160 projects from 111 different organizations were referenced. With an average length of 89 minutes, the interviews produced 22 h and 20 min of relevant discourse, which when transcribed, came to 137,495 words. Table 1 provides a break down of these figures for each participant along with information about their levels of experience.

As well as eliciting a substantive quantity of data, from their facial expressions, postures, pauses, and questions, it was constantly apparent that participants were thinking deeply. Indeed, postinterview some explicitly expressed that this had been the case. Some said that the process had helped them to learn from their own experience, one requested a copy of the audio files for further reflection and another expressed surprise at his own knowledge.

It was also apparent that the infographics had supported the learning process. Without prompting, three participants made positive comments about them. All focused on them and in some way handled them, either tapping, stroking, holding,

Table 1 Basic information about research participants and interlocutions

Participant number	Interview duration (minutes)	Number of organizations that the participant has worked for full time	Years of user acceptance experience	Projects or Systems Referenced	Organizations involved
1	102	1	10	6	2
2	106	1	15	11	11
3	101	6	34	16	11
4	96	2	10	12	3
5	78	1	10	9	8
6	84	6	41	22	20
7	94	1	33	8	5
8	108	1	8	7	1
9	85	8	15	14	8
10	77	1	14	9	1
11	70	6	14	7	8
12	52	3	30	6	2
13	87	18	26	14	14
14	91	1	28	5	5
15	109	4	14	14	12
Total	1340	60	302	160	111
Average	89	4	20	11	7

or flicking between them. The effectiveness of each graphic and explanation however differed between participants. Although all participants claimed to understand all of the theories presented, the degree of discourse elicited by each was variable. That which invoked a 40 minute reflection with one participant invoked nothing with another. Given this unpredictability, it was beneficial that a range of theories and infographics were at hand.

With respect to candidate selection and the proposed definition of expertise, as all interviews were effective, this had clearly been adequate. It was apparent, however, that the most impressive insights tended to come from older candidates with over 25 years of experience, suggesting that a status of “elder expert,” unrecognized by this method, may have been beneficial. The intensity and momentum of the discourse was also aided by the researcher also being an “expert” who accordingly understood industry trends, history, and shibboleths. This became evident when during the tenth interview a “PDM system” was mentioned, something of which I had no knowledge. At this point, the interview digressed for 439 words while I acquired an understanding adequate to continue. This deviation constituted about 5% of that interview. An apparent limitation, therefore, is that this method can not tolerate many such examples of interviewer ignorance.

A final observation is the breadth of discussion that was invoked. As an inductive investigation, this was beneficial, drawing out events from any number of projects in each participant’s career. Care did need to be taken, however, to retain a boundary, in this case ensuring that only Information System implementations were being discussed. Participants easily, for example, digressed onto “attitudes towards cycling helmets” and responses to government legislation. Although such tangents were discouraged, they support the proposition that this method could be reapplied to acceptance in other scenarios.

8 Conclusion and Future Direction

This research has demonstrated that pedagogy supported by graphics can assist in the elicitation of expert knowledge. In this case, the focus was the introduction of new Information Systems, but with little adaption the same method could be applied to elicit expert knowledge on the acceptance of other change, such as changes to organizational structures, quality systems, work-related procedures, regulations, legislation, or corporate strategy. Using different theory and graphics, it is also believed that this method could be adapted to elicit expert knowledge in a range of different domains.

An apparent limitation of the method is the required level of interviewer competency. As it stands, they must have both an expert knowledge of the subject matter and the ability to educate. In this case, as theoretical saturation was reached quickly, it was not an obstacle, but in other applications where participants are more geographically dispersed or numerous, it could be problematic. To overcome this, a more systematic version of the method might be developed. Could the learning for example be facilitated by e-learning and a standard set of follow-up prompts

devised? If the process could be simplified or automated, this would enable more interviewers to be involved and/or more participants to be reached, increasing the range of research areas to which it might be applied.

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A

- Aboriginal Chronic Disease Support Group, 1574
- Aboriginal people, 1713–1716
 - equality, 1712
 - ethical approval, 1717–1718
 - historical research, awareness of, 1711–1712
 - National Aboriginal and Torres Strait Islander Suicide Prevention Strategy, 1716
 - participatory action research, 1717
 - principles of research, 1714–1715
 - reciprocity, 1712
 - reporting and disseminating findings, 1718–1719
 - research participants, 1718
 - respect, 1712
 - responsibility, 1713
 - spirit and integrity, 1712
 - suicide in Aboriginal communities, 1709–1711
 - survival and protection, 1713
- Aboriginal people, in Australia
 - cultural protocol, 1567
 - data collection, for research, 1568–1569
 - focus groups, 1569
 - grounded theory, 1567
 - Health workers, 1566
 - professional identity, 1566
 - research findings, 1571–1572
- Academic presentation, research findings and public policies, *see* Research findings and public policies
- Access negotiation, 2189–2190
- Accountability, 274
- Adapted alternating treatments design (AATD), 592
- Adaptive randomization, 649
- Adequate randomization methods, 648
- Ad-hoc approach, 1937
- Adorno, Theodor W., 136
- Advocacy, 54, 56, 57, 59, 1885
- Africana womanism, 1582
- Africanist Sista-hood in Britain, 1581–1584, 1595–1597
- Agency, 2012, 2018
- Alcohol Use Disorders Identification Test (AUDIT), 1980
- Allegiance, 2083–2085
- Allocation concealment, 649
- Alternating treatments design (ATD), 590–592
- Altruism, 77
- Ambivalence, 2087–2089
- A Measurement Tool to Assess Systematic Reviews (AMSTAR 2), 1030
- American Anthropological Association, 429
- American Oral History Association, 430
- American Time Use Survey (ATUS), 1226
- Analysis, 918, 919
 - data management, 922–924
 - data selection, 920–922
 - goals of, 919–920
- Analysis of networks, 770
- Analysis of variance (ANOVA) approach, 612–614
- Analysis procedures, 863, 870, 873, 878
- Analytic reflexivity, 514, 515
- Animated visual arts researching, 2100
 - background projects, 2094–2098
 - fragments and vignettes, 2101–2103
 - health condition symptoms, 2099–2100
 - humor incorporation, 2103–2104
 - invisible visualisation, 2105–2106
 - penetration, 2106
 - snapshots, 2100, 2101

- Animated visual arts researching (*cont.*)
 thumbnails, 2100, 2101
 triangulated heuristic framework,
 2098–2099
 Animation, *see* Animated visual arts
 researching
 Anonymity, 1358–1360, 1978–1979
 Anorexia, 100
 Antirealism, 162–163
 Aotearoa New Zealand, 1508, 1511
 Application programming interfaces
 (APIs), 501
 Applied conversation analysis, 484–485
 Appraisal, 1014–1016, 1022, 1023, 1025
 criteria for, 1014
 guidelines, 1024
 qualitative research, 1015–1017
 qualitative studies, 1015
 Array factor, 758–761
 Arts-based health research, 1304, 1316
 Arts-based methods, 1256, 1262
 Arts-based research (ABR)
 arts and health movement, 1136
 creative arts therapies, 1136–1138
 creative insight method, 1077
 definition, 1076, 1132
 example, 1138–1139
 methodology in healthcare, 1133–1134
 narrative writing, 1141–1142
 poetry writing, 1142
 theoretical location, 1134–1136
 visual arts, 1142
 Assent, 1998
 Asylum seekers, 1812, 1816, 1823, 1825,
 1873–1874
 Asynchronous email interviewing method,
 1084
 Attachment, 1898
 Attention-deficit hyperactivity, 108, 111
 Attention probes, 406
 Attributable proportion, 570
 Audience(s)
 analysis, 357–359, 362
 and online face-work, 1358–1360
 AUDIT, *see* Alcohol Use Disorders
 Identification Test (AUDIT)
 Australia, 1692, 1694, 1695, 1697, 1699, 1702
 Autism spectrum disorder (ASD), 1158
 Autobiographical narrative, 414–415
 Autoethnography, 1504, 1830, 1832–1834,
 1836, 1840, 1842, 1843
 analytic, 514–515
 characteristics, 515
 data analysis, 519
 description, 510, 513
 design questions for, 516–518
 methodological parameters, 511
 methodology, 515
 theory and methods, 511
 Automethodologies, 511–513
- B**
 Background/introduction (BI) section, 988–989
 Bakhtin, Mikhail, 2069, 2075, 2076
 authoritative and internally persuasive
 discourse, 2065
 dialogism, feminist approach to, 2063
 Bayesian meta-analysis, 790
 Being
 and becoming, 194–195
 language, 197–198
 meaning, 193
 thereness of, 193–194
 in world of care, 195
 Best worst scaling (BWS)
 DCE, 633–634
 objects, 631–632
 profile, 632–633
 Bhaskar, Roy, 161, 164, 165
 Bias(es), 238, 239, 241, 248, 250, 251, 666, 667
 Biological plausibility, 576
 Biomedical model, 104–105
 Biopsychosocial model, 105–106
 Black feminism, 1582, 1583
 Black women
 insider/outsider research, 1582, 1583, 1586,
 1588, 1590, 1591, 1593, 1595, 1596
 working in public sector, 1581
 Blinding, 649–650
 Block randomization, 648
 Blogs/Blogging, 1083
 and confessional society, 1355
 as documents of life, 1356–1358
 Blogs in social research
 data analysis, 1361–1362
 data collection, 1360–1361
 ethics, 1362–1364
 qualitative research, 1354, 1359
 Body mapping
 definition, 1238–1239
 ethical aspects of, 1251–1253
 examples, 1241
 history of, 1240
 method, 1080–1081
 planning for study, 1241–1245

- process of, 1239–1240
 - research using, 1246
 - as therapeutic tool, 1240
 - uses, 1241
- Bottom-up cueing, 1227
- Breaching, 277
- Breastfeeding, 1765, 1766, 1768, 1770, 1772
- BringItOn, 360
- Brokerage, 773, 774, 777, 780
- Bronfenbrenner's ecological systems theory, 1203
- BWS, *see* Best worst scaling (BWS)
- C**
- Calendar methods, 1225
 - health-related issues, 1231–1233
 - self-administered, 1231
 - well-being and surveys, 1224–1227
- Canada, Australia, Aotearoa New Zealand and the United States (CANZUS), 1503
- Card-based discussion method, 1171–1172
- Cartoon captioning, 2030–2031
- Case control study, 565
- Case study research, 318
 - advantages of, 323–324
 - definitions, 319–320
 - generalization (*see* Generalization)
 - limitations of, 321–323
 - multiple-case design, 321
 - single-case design, 321
- Cellphone surveys, 1084
 - epidemiological biases (*see* Epidemiological biases, in cellphone surveys)
 - mobile phone subscriptions, 1404–1405
- Central organizing concept, 845, 856
- Centre for Digital Storytelling (CDS), 1305
- The Centre for Evidence Based Medicine's systematic review appraisal tool, 1030
- Centre for Oral History and Digital Storytelling, 430
- Channel analysis, 358
- Children, 2008–2009
 - cultural dimension, 2010–2012
 - ethics and research with, 2016–2017
 - psychological dimension, 2012–2013
 - research methods (*see* Research methods)
 - socio-political dimension, 2009–2010
- Children's perspectives on health and illness, 1726
- Child sexual abuse, 2062, 2065, 2066, 2070–2073, 2075, 2076
- Choice of analysis model, 957, 965
- Clarification probes, 406
- Classic question response model, 1226
- Cluster analysis, 950
- Cluster randomized trials, 655–656
- Cochrane Qualitative and Implementation Methods Group (CQIMG), 787
- Code, 847, 848, 855
 - deductive orientation, 853
 - inductive orientation, 853
 - latent, 853
 - semantic, 853
- Codebook, 847, 849
- Coding, 303–306, 918, 920, 922, 923, 926–931, 933, 934
 - reliability, 847–849, 857
- Cognitive impairment, 1983–1985
- Cohort study, 565
- Collaboration, 385, 416, 771, 772, 774, 776–778, 1519, 1712, 1713, 1716, 1718, 1719
- Collage, 1746, 1747
- Collective analysis, 534, 536
- Collective memory, 426
- Colonization, 255–257, 1692, 1695, 1698, 1699
- Coming Through*, 2094, 2097, 2103, 2106
- Community-based participatory research (CBPR), 1850, 1854, 1863
 - community participation, 289–290
 - community strengths and dynamics, 292
 - definition, 286
 - design and conduct research, 293
 - disseminate and translate research findings, 293
 - feedback and interpret findings, 293
 - health priorities, 292–293
 - methodological and ethical considerations, 295
 - partnership, 292, 294
 - power equilibrium, 290
 - principles, 288–289
 - research process, 291
 - social justice and equity, 291
 - training, 294
- Community case management (CCM), 339
- Community engagement, 1567, 1576, 1577
- Community-Up approach, 1517
- Comparative effectiveness research (CER), 378, 659
- Complementary research methods, 1184
- Computer-assisted interviews (CAIs), 1778
 - accessible and attractive interfaces, 1782
 - children's agency and control, 1781–1782

- Computer-assisted interviews (CAIs) (*cont.*)
 quantitative and qualitative analyses, 1782
 refugee children's well-being, 1783–1789
- Computer-assisted qualitative data
 analysis, 1248
- Comte, Auguste, 154, 156, 157
- Concept maps, 1745, 1750
- Concourse, 754–755
- Concurrent triangulation design, 701–702
- Confessional society, blogging, 1355
- Confidentiality, 1897
- Confounding, 572
- Connectivity, 772
- Consensus, 717–719, 721
 methods, 739, 746
- Consent, 1996–1999
- Consistency, 576
- Consolidated Criteria for Reporting Qualitative
 Health Research (COREQ), 973, 1052
- Consolidated Standards of Reporting Trials
 (CONSORT) statement, 972, 987, 1040
- Construct elicitation, 1101–1103, 1105
- Constructive alternativism, 1096
- Constructive empiricism, 163
- Constructivism, 58, 60, 834–835, 1098, 1116
- Constructivist epistemology, 1096–1097
- Constructivist GTM (CGTM), 301
- Constructivist paradigm, 1655, 1656
- Constructivist research, 300–303, 307–308,
 311–313
- Constructivist sensibility, 1135
- Constructivist theories, 1097
- Construct validity, 670–671
- Construing, 1097–1098, 1100, 1103
- Consumers, 1936, 1944
- Contact varieties, 1622
- Content analysis (CA), 178–179, 901
 conventional, 830
 and critical realism (*see* Critical realism)
 definition, 828–829
 directed, 830
 history, 830
 qualitative descriptive studies, 836
 summative, 829–830
- Content validity, 670
- Continuation probes, 406
- Conventional content analysis, 830
- Convergent design, 63
- Convergent parallel, 701–702, 705
- Conversation analysis, 278
 applications, 483–485
 data analysis, 479–483
 data collection, 477–479
 description, 472
 development, 473–474
 empirical ground of analysis, 475
 institutional interactions, 475–476
 methodological foci, 474
 sequential organization, 475
 structural organization, 474–475
- Conversation Analytic Roleplay Method
 (CARM), 484
- Conversion hysteria, 213
- COREQ checklist, 975
- Co-research, 1947
- Cost-benefit analysis, 361
- Creative arts practice, 2106, 2107
- Creative arts therapies, 1136–1138
- Creative research methods, 1188
 See also Innovative research methods
- Credibility, 1964
- Crisis in social psychology, 119
- Criterion validity, 671–672
- Critical alternatives, 106–108
- Critical appraisal
 definition, 1028
 mixed methods research (*see* Mixed
 methods research)
 observational studies, 1040–1046
 skills, 1028, 1029
 systematic reviews, 1029–1034
- Critical Appraisal Skills Programme (CASP)
 checklist, 1030
- Critical discourse analysis (CDA), 128–129
- Critical ethnography, 511
 description, 225
 HIV, marriage and mining in Papua New
 Guinea, 229–231
 objective-subjective dichotomy, 232–234
 reflexivity, 231–232
- Critical interpretive synthesis, 789
- Critical psychology, 126
- Critical realism, 164–165
 actual reality, 834
 constructivism, 834
 critical theory, 835
 definition, 832
 empirical reality, 834
 knowledge production, 833
 mechanisms, 833
 positivism, 834
 qualitative descriptive research, 836
 real, 834
 social norms, 833
 social structures, influence of, 833
 use of, 837–839

- Critical reflexive practice, 262
 Critical Skills Appraisal Program (CASP), 1052
 Critical theory, 134, 135, 137, 835
 epistemological content of, 136–140
 epistemology, 134
 method of, 140–143
 normative turn, 143–147
 political epistemology, 135
 Cross-cultural research, 1499
 Cross disciplinary research, 198–201
 Cross-language research strategy
 finding capable interpreters, 1641–1643
 social position and subjectivity, of
 interpreters, 1643–1646
 survey translation, 1646–1647
 in Uganda, 1647, 1649
 Crossover designs, 605, 607–609
 Crossover studies, 656–657
 Cross sectional study, 565
 Crystallization, 519
 Cultural awareness, 239, 245–246
 Cultural dimension, 2010–2012
 Culturally and linguistically diverse (CALD)
 communities, 227
 Culturally Deaf women, 1580, 1581, 1590
 interviewing in sign language, 1585, 1587
 Cultural materialism, 458
 Marxist, 462
 Cultural research on human development,
 ethical issues, *see* Ethical issues,
 human development
 Cultural responsiveness, 1527, 1539
 Cultural safety, 1526, 1527, 1529, 1530
 Cultural understanding, 1831, 1832
 Culture, 225, 301, 307–310, 313, 314
 as an object of intervention, 227–228
 ethnographic tradition and critique, 226
 structural determinants of disempowerment
 and health, 228–229
 Cumulative duration, 946
- D**
Dasein, 193
 Data analysis, 29, 41, 45–47
 Data collection, 416, 991, 1118, 1568–1569,
 1975, 1979, 1982, 1984
 Data enhancers, 17–18
 Data quality, mixed methods research
 analytic adequacy, 1060
 analytic integration rigor, 1060
 data rigor, 1059
 data transparency, 1059
 sampling adequacy, 1059
 Data saturation, 19
 Decision analysis (DA), 380
 Decision-making tools, translational research,
 see Translational research
 Decolonization, 1510, 1512, 1521
 Decolonizing methodologies, 1544,
 1545, 1547, 1549, 1551,
 1552, 1555
 Decolonizing research, 1852–1855, 1865
 Deliberation, 1169
 Delphi technique, 716, 731
 applications, 718
 modifications, 724
 qualitative-quantitative design, 730
 question types, 717
 roles, 718
 Dementia, 1992
 consent, 1996–1999
 DEEP, 1993
 methodological considerations for research,
 2000–2001
 people recruitment, 1994–1996
 perceptions of, 1992
 research methods and approaches,
 1999–2000
 Dementia Engagement and Empowerment
 Project (DEEP), 1993
 Demonstration designs
 for non-reversible behaviors, 589–590
 for reversible behaviors, 588
 Descriptive study, 565
 Designing for dissemination and
 implementation (D4D&I), 368, 372
 Design quality, mixed methods research
 design rigor, 1059
 design strength, 1059
 design suitability, 1059
 design transparency, 1058–1059
 Development, 1681, 1686, 1688
 Dewey, John, 158
 Diabetes care, for Aboriginal people,
 see Aboriginal people, in Australia
 Dialectics, 134, 136–139
 and intersubjectivity, 143
 Digital afterlife, 1314–1315
 Digital methods
 advantages, 1082
 asynchronous email interviewing method,
 1084
 blogs, 1083
 cell phone survey, 1084

- Digital methods (*cont.*)
 netnography, 1083
 phone survey introductions and response rates, 1084
 synchronous text-based online interviewing method, 1084
 web-based survey methodology, 1083
 Digital story sharing, 1312–1314
 Digital storytelling (DST), 437, 1304–1305, 1879
 codified process, 1305–1306
 defined, 1305
 elements of, 1306
 initiating critical dialogue, 1307–1314
 method, 1081
 negotiating voice, 1310–1312
 voice produce, 1309–1312
 workshop-based practice, 1306–1307
 Diglossia, 1622
 Directed content analysis, 830
 Disability, 1939–1941
 interview methods for child with (*see* Interview methods, disabled children)
 and sexuality, 1956–1957
 Discourse analysis (DA), 128, 882
 components of, 887
 and discursive psychology, 882–884
 and FDA, 884–886
 feminist discourse analysis, 887–893
 Discrete choice experiments (DCEs), 624, 625, 627, 629, 631, 633, 634
 attributes and levels, 636–638
 cognitive burden, 635
 comparative study, 635
 data collection, 640
 experimental design, 638–639
 health-related research, 627, 635
 reporting, results, 640
 statistical analysis, 640
 UK study of preferences, 628
 Discursive practices, 885, 886
 Discursive psychology (DP), 129–130, 882–884, 887
 Disease, 101
 Displacement, 1762, 1773
 Display of family life, 1466
 Distress, 1981–1983
 Documents of life, blogs as, 1356–1358
 Dominant western paradigm, 263
 Donor-driven prevention programs, 231
 Dose-response, 576
 Drapetomania, 107
 Drawing, 2070, 2072–2076
 Drawing method
 adult participants, 1762
 breast milk, 1772, 1773
 cultural beliefs, 1768
 data collection, 1765
 draw and talk/draw and write techniques, 1762
 empathy, 1765
 empowerment, 1767
 encouragement, 1765
 ethnicity, 1763
 freedom in Australia, 1771–1772
 motherhood, 1769–1770
 mother's rejection, 1765
 postmodernism, 1761
 refugee backgrounds, 1762–1763
 “trial-and-error” adjustments, 1764
 vulnerability, 1770–1771
 Drug use, 1975, 1976, 1978, 1980, 1982, 1985
 DST, *see* Digital storytelling (DST)
 Dual frame telephone surveys, 1405–1407
 Dubbo Aboriginal Research Team, 1567
- E**
 Eating disorder, 2062, 2065–2068, 2070–2073, 2075, 2076
 Ecological study, 566
 Ecological systems theory, 1203
 Effect size test, 674
 Electronic interview via email, 1390–1395
 Elites, 1907, 1909, 1914
 health (*see* Health elites)
 Email
 as communication and research tool, 1387–1390
 delayed responses and absence of punctuation, 1396
 electronic interview via, 1390–1395
 indirect contact and body language, 1396–1397
 informality, 1397–1398
 as interview tool, 1395–1398
 sampling possibilities and cost-effectiveness, 1398
 validation, 1397
 Emancipation, 1741
 Emancipatory research, 1938
 Embedded design, 702–703
 Embodiment research, 1080–1082
 Emoticon, 1396

- Emotional labor, 2147
- Emotions and sensitive research
 - data analysis, 2150–2151
 - data collection, 2149–2150
 - emotion work, 2146–2148
 - ethics, 2148–2149
 - informal support, 2154–2155
 - protocols and guidelines, 2155–2157
 - research assistants, 2152–2153
 - secondary data, 2153–2154
 - transcriptionists, 2151–2152, 2157–2158
- Empathic testimonial approach, 1925
- Empathy, 238–240, 246
 - interdisciplinary, 240–241
 - limitations, 250–251
 - modes of, 241–243
 - practicing, 243–250
 - risk of, 250–251
 - self-reflection, 248–250
 - situational, 243
- Empirical studies, 992
- Emplacement, 1276
- Empower, 1169
- Empowerment, 1741
- End-of-life care, 828, 836, 837, 839
- Endometriosis, 215
- Engagement, 1168, 1170
 - choreography, 1177
 - public, 1169, 1171, 1177, 1179
 - rethinking, 1168
- Enhancing the Quality and Transparency of Health Research (EQUATOR) Network, 972
- Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement, 973, 977
- Epidemiological biases, in cell phone surveys
 - cost-efficiency and feasibility, 1412–1413
 - non-coverage bias, 1408–1410
 - non response bias, 1410–1411
- Epidemiology, 561
 - causes, 573–577
 - challenges, 577–578
 - confounding, 572
 - descriptive, 561
 - determinants, 561
 - experimental study, 564
 - history of, 561–563
 - measurement error, 573
 - observational study, 565–566
 - random error, 571–572
 - selection bias, 573
- Episodic records, 496–497
- Epistemology, 102–104, 152, 154, 159–161, 167, 225, 853, 857
 - arts-based research, 1138–1139
- Equity, 287, 291, 295, 296
- Ethical issues, human development
 - children's folk-biological reasoning, 1900
 - developmental research, 1901
 - harm, 1898–1899
 - informed consent, 1895–1897
 - privacy, 1897–1898
 - psychological research, 1900
- Ethical standards
 - beyond purview of review boards, 2172–2173
 - formal review boards, 2171–2172
- Ethics, 431, 536–537, 1882–1884, 1936, 1943, 1949, 1974–1975, 1977, 1979, 1994, 1998, 2128–2130, 2135, 2136, 2140, 2141, 2148–2149
 - of silence, 435
- Ethnographic methods, 232, 444, 511
 - advantages, 452
 - criticisms of, 453
 - future research, 453–454
 - innovative forms, 449–452
 - reflexivity, 446–447
 - traditional approaches, 447–449
- Ethnography, 226, 2199, 2208, 2209
 - critical challenges to, 468
 - definition, 458
 - model of, 458
 - symbolic interactionism, 176–177
- Ethnomethodology, 473
 - accountability, 274
 - in action, 280–281
 - breaching, 277
 - and common sense procedures, 276
 - and conversational analysis, 276, 278
 - data collection techniques, 277–278
 - description, 271
 - emergence of, 272–273
 - and ethnography, 278
 - indexicality, 275
 - membership categorization analysis, 275–276
 - perspective, 271–272
 - practicalities, 279–280
 - reflexivity, 274
 - role of, 270
 - strengths and advantages, 279
 - weaknesses and limitations, 278–279
- Evaluation indicators, 345–347

- Evaluation research, 356
 culture/ethnicity, 350
 development of indicators, 347–350
 evaluation indicators, 345–347
 features of, 335
 formative, 357–359
 gender-sensitive indicators, 350–351
 logic models and results based frameworks, 340–342
 PRECEDE-PROCEED model, 342
 process, 359–361
 purpose and phases of, 344–345
 realistic evaluation theory, 340
 study designs and methodologies for, 346
 summative, 361–362
 ToC (*see* Theory of change (ToC))
- Evidence-based health care, 3
- Excellence in Research for Australia (ERA), 368
- Expanded bioecological theory, 1203
- Expert(s), 716, 717, 719–722, 724, 1907, 1909, 1915, 2214–2216
- Expertise, 2214–2216, 2222
- Expert knowledge elicitation, 2214
 cognitive dissonance theory, 2218–2219
 learning based knowledge elicitation, 2216–2218
 research interviews, 2219–2221
 research participants and interlocutions, 2221
- Explanatory sequential design, 63–64
- Exploitation, sexual, *see* Sexual exploitation
- Exploratory sequential design, 64–65
- Expressive therapy, 1135
- External validity, 373, 375, 383–384
 online survey research, 1344, 1350
- F**
- Facebook, 359
- FaceSpace Project, 361
- Face-to-face recruitment, 86, 87, 91
- Face-to-face research in prisons
 ethics, 2170–2171
 with prisoners, 2166–2167
- Face-to-face (F2F) surveys, 548, 554, 555
- Facilitator, 741
 orientation, 1800, 1802, 1804
- Factorial design, 654–655
- Faith-based HIV prevention programs, 229
- Feminism and healthcare
 description, 206–207
 politically, historically and culturally embedded healthcare, 207–208
- Feminist, 2112–2113, 2121
 methodology(ies), 458, 462, 2080–2083
 paradigm, Bakhtinian theoretical framework (*see* Bakhtin, Mikhail)
- Feminist discourse analysis
 aim and method, 887–888
 PMS (*see* Premenstrual syndrome (PMS))
- Feminist pragmatist model
 description, 209–210
 radical objectivity, 218
 relational and systems critical approach, 218
 solution-focussed epistemology, 216–217
- Fidelity research, 381–383
- Fieldwork, 447, 1676, 1679, 1682, 1684, 1687, 1688
- Flexible conversation techniques, 1225
- Focus group(s), 740, 743, 747, 975, 979
 research, 1800–1802, 1807
- Forecasting, 716–718
- Forest plots, 821
- Formal review boards, 2171–2172
- Formative evaluation, 357–359
- Foucauldian discourse analysis (FDA), 128–129, 884–887
- Four-phase model, timelines, 1197–1198
- Fragmented narrative communication, 2094, 2101
- Frankfurt School's method, 140
- Freelister, 1439
- Freelisting, 1432–1443
 advantages, 1433, 1434
 analysis, 1438–1440
 domain analysis, 1436–1438
 method, 1085
 obstacles of using, 1433
 potential shortcoming of, 1434
 recognition of, 1432
 salience analysis, 1438
 systematic data collection, 1441
 with ethnographic interviews, 1440–1443
 written, electronic and oral interviews, 1435–1436
- Free recall, 1438
- Freund, Alexander, 435
- Funnel plots, 822
- G**
- Gender equality, 211–212
- Gender sensitive evaluation, 350–351
- Generalization
 analytical, 325
 formal, 318, 324

naturalistic, 326–329
 nomothetic, 325
 statistical, 325
 Generative taxonomy, 503
 Genuine integration, 686
 Go-alongs, *see* Walking interviews
 Good reporting of a mixed methods study
 (GRAMMS) tool, 1062
 Grammatical issue, 1623
 Graphic elicitation, 1195
 Grounded theory methodology (GTM)
 approaches, 301
 characteristics, 302
 coding, 303–306
 constructivist, 301, 307–308
 conventional approaches, 306
 describes, 300
 in health social science, 308–314
 process of, 302
 value of, 301
 Grounded theory research, 1655, 1656
 Group allocation, 1037
 Group discussion, 1169

H
 Habermas, Jürgen, 141, 142
 Hard-to-reach people, 1907, 1910, 1914
 Harm, 1892, 1898–1899
 reduction, 1979
 Healing culture, 261
 Healthcare personnel, 209, 215–216
 Health disparities, 1851–1852
 Health elites, 2199, 2209
 clinic and laboratory, 2203–2205
 conferences, 2205
 documentary cultures of, 2206
 and ethical issues, 2200–2201
 interviewing, 2202–2203
 patients, 2207
 sampling and access, 2201–2202
 social scientists, 2208–2209
 Health inequities, 1851–1852, 1862
 Health information systems
 formative research, 357–359
 process evaluation research, 359–361
 summative evaluation research, 361–362
 Health information technologies (HITs), 356
 Health promotion, 514, 516, 520, 522, 524,
 525, 1544, 1546, 1550, 1552
 Health social sciences research
 critical realism in, 165
 netnography in, 1324
 post-positivism in, 160

Heidegger, 191
 See also Hermeneutics
 Hermeneutics, 190
 cross disciplinary research, 198–201
 current neglect of, 191–193
 in research, 191
 tenets of, 193–198
 Heterogeneity, 808, 812, 815, 819, 821
 Heuristic research, 2098–2099
 Hidden populations, 1907, 1911
 History, content analysis, 828, 830–832
 HIV/AIDS, 1152–1158
 Home–school communication, 1468–1474
 Horkheimer, Max, 136
 Hull Floods project, 1450
 Human health, 105, 107
 Hybrid design, 66–67
 Hybrid trial designs, 375–376
 Hysteria, 213
 Hysterical women, 213–215

I

IMAGINE, 1173
 analyzing, 1179–1180
 application/situation cards, 1174–1175
 card types and choreography, 1174–1176
 challenges, 1169–1170
 discussion groups groups, 1177–1179
 exploring and analyzing the issue,
 1172–1174
 future cards, 1175–1176
 issue/context cards, 1175
 story/statement cards, 1174
 validating the card, 1176–1177
 Incidence, 567–568
 Inclusion, 1170
 Inclusive research, 1936
 academic researcher experiences,
 1944–1945
 ad-hoc approach, 1937
 characterization, 1937
 components, 1938
 co-researcher experiences, 1942–1944
 co-researcher involvement, 1941–1942
 disability, 1939–1941
 methodological issues, 1945–1948
 In-depth interviewing method, 17
 In-depth interviews, 393, 396, 402
 Indexicality, 275
 Indigenist paradigm, 262
 Indigenist research, 1545, 1548–1559

- Indigenous Australians, 1544, 1546
- Indigenous Knowledge, 260–261
- Indigenous people(s), 1508, 1511, 1514, 1848, 1854, 1856, 1858, 1861–1863
- Indigenous research, 1528, 1531, 1533, 1541
- Indigenous statistics, 1697–1698
 - Aotearoa New Zealand, Māori families, 1699
 - Australia, Indigenous children's education, 1702–1703
 - development principles, 1696
 - Indigenous data sovereignty, 1696–1697
 - social norms, values and racial hierarchy, 1699
- Indigenous ways of knowing, 1796, 1797, 1801, 1807
- Individualized profiles, 1782
- Infant feeding
 - cultural perspectives, 1767
 - ethnographic studies, 1761
 - refugee backgrounds, 1763
 - refugee perspectives of, 1768
- Inference transferability, mixed methods research, 1061–1062
- Infographics, 2214, 2217, 2221
- Information computer technology (ICT) surveys, 551
- Information systems practitioners, 2214
- Information systems research, 2214
- Informed consent, 1893, 1895–1897
- Innovation, 688–689, 1169
 - new perspectives on, 1169
- Innovative researcher, 1074–1075, 1087
- Innovative research methods
 - arts-based and visual methods, 1076–1080
 - body and embodiment research, 1080–1082
 - classification, 1073
 - definition, 1073
 - digital methods, 1082–1085
 - as emerging research methods, 1074
 - innovative researcher, 1074–1075
 - mind maps in qualitative research, 1076
 - personal construct qualitative methods, 1075
 - textual methods of inquiry, 1085–1087
- Insider(s), 1609–1610
 - perspectives, 1958–1959
- Insider/outsider research
 - Africanist Sista-hood in Britain, 1581–1584, 1592–1597
 - data collection, 1585–1587
 - design, 1581
- Institutional discourse, 460, 461, 464
- Institutional ethnography (IE)
 - data collection, 466–467
 - described, 458
 - framework, 459
 - Marxist cultural materialism, 462
 - recent works, 459
 - work places, 459
- Instrumentalism, 163
- Integration
 - description, 685
 - genuine, 686
 - multistream visual data, 689
 - principles and practices, 686
 - researcher role, 687–688
- Interactions, 472
 - health care, 483–484
 - institutional, 476
 - See also* Conversation analysis
- Internal consistency reliability test, 668–669
- Internationalization of English, 1621
- Internet, 1387
 - and deceptive responses, 2138–2139
 - desk research, 2130–2132
 - online ethnography, 2136–2138
 - online materials, 2132–2133
 - and participant recruitment, 2133–2135
 - and sexual subculture participant recruitment, 2135–2136
 - and truthful responses, 2139–2140
- Interpretation, 29
- Interpreters, 1655, 1657–1658, 1662, 1665–1668, 1671
- Interpretive hermeneutic phenomenological approach (IHPA), 1959, 1968
 - foundational tenets, 1959–1963
 - strengths and limitations, 1969–1970
 - trustworthiness, 1963–1968
- Interpretive rigor, mixed methods research
 - interpretive agreement, 1061
 - interpretive bias reduction, 1061
 - interpretive consistency, 1061
 - interpretive correspondence, 1061
 - interpretive distinctiveness, 1061
 - interpretive efficacy, 1061
 - interpretive transparency, 1061
 - theoretical consistency, 1061
- Interprofessional relationships, 772
- Inter-rater/inter-observer reliability test, 668
- Inter-subjectivity, 413
- Intervention design, 65–66
- Interventionism, 227–228

Intervention research, 584, 587, 589, 598
 Interview(s), 173, 975, 979, 980, 1115, 1655,
 1657, 1658, 1661, 1663
 data transcription, 1670
 interview guide, 1664–1665
 language use, 1667–1668
 materials, 1394–1395
 participants, contact, 1391–1392
 participants selection, 1391
 questions, 1390–1391, 1393
 second interviews, 1668–1669
 study design, 405
 Interviewers, 549–551
 Interviewer speech vs. voice/vocal
 characteristics, 1418–1420
 minimizing non response, 1420–1423
 Interview methods, disabled children
 cartoon captioning, 2030–2031
 child-researcher power relations,
 2036–2038
 partnering with parents, 2035–2036
 photo-elicitation, 2032
 role play, 2029
 sentence-starters, 2034–2035
 stage setting, 2034–2035
 vignettes, 2033–2034
 Interview tool, email as, 1396
 Intoxication, 1975, 1981, 1983
 Investigator, participant interface, 73–74
 Involvement of people with dementia,
 1993–1995, 1997
 Irish Republican Army (IRA), 433

J

Jeffersonian transcription system, 486
 Joanna Briggs Institute's critical appraisal
 tool for systematic reviews, 1030
 Journalling, 920, 926
 audit trail, 920, 926

K

Kaupapa Māori health research, 1500
 axiology, 1516–1520
 epistemology, 1514–1515
 methodology, 1515–1516
 ontology, 1512–1513
 paradigm, 1511–1512
 kaupapa Māori research, 1531, 1533
 Key performance indicators (KPIs), 362
 Kinetic conversations, 2036

Knowledge, 3, 4, 6, 1002
 exchange, 777, 780
 research, 1003–1006
 scientific, 1006
 social, 1000
 transfer, 1005, 1007

L

Laddering method, 1102–1104
 Ladder of participation' model, 1927
 Language, qualitative research, *see* Qualitative
 research, multiple language groups
 Language interpretation, 1640, 1641, 1649
 Latent, 853
 Latvian Legal Reform Project (LLRP), 1123
 Law enforcement and public health (LEPH),
 2181, 2187, 2193
 Lay-expert divide, 1180
 LEPH, *see* Law enforcement and public health
 (LEPH)
 Levels of measurement
 definition, 957
 and descriptive statistics, 959
 interval measurement, 958
 nominal measurement, 957
 ordinal measurement, 957
 ratio measurement, 958
 significance of, 956–957
 Lexical issue, 1619, 1628
 Lexicographic pattern, translation,
 see Translation
 LHC method, *see* Life history calendar (LHC)
 Life course, 938–940, 1202
 Life course theory, 1203–1204
 Life grids, 1186
 timelining method, 1193
 Life history calendar (LHC), 1202, 1204–1205
 adaptation of, 1209
 evolution of, 1205–1207
 implementation, 1210–1215
 method, 1079, 1194
 qualitative study, 1207–1210
 Life history data, 941, 950
 Life history interview, 426, 427, 430, 432, 434
 analyzing and disseminating, 435–438
 described, 426
 preliminary considerations, 428–430
 Life story mapping, 1194
 Life world, 412
 Lingua franca, 1621
 Linguistic contact, 1622
 Linguistic treatment, 1623–1624

- Literature, 920
- Lived experience, 414, 450, 453
- Living historically, 536, 538
- Logical framework approach (LFA), 340, 341
- Logical positivism, 157, 160
- Longitudinal data, 619
- Longitudinal study designs
 - advantages and problems, 605–606
 - follow-up studies, 606
 - repeated measures (*see* Repeated measures)
- Luo medical culture, 1727

- M**
- Māori, 1527, 1529–1531
- Māori-centred research, 1533
- Marcuse, Herbert, 136
- Marginalized people, 1909, 1910
- Masturbation, 107
- Materiality, 1177, 1179
- Maternal Early Childhood Sustained Home-visiting (MECSH[®]) program, 373, 387
- MAXQDA, 926
- Meandering timeline, 1186
- Meaning-making, 417
- Measurement, 664
 - aetiology, 675–676
 - decision-making, 677
 - error, 573
 - evaluation of interventions, 676
 - monitoring, 676–677
- Measures of association
 - OR, 569
 - RR, 568
- Media outreach strategies, 91
- Medical sociology, 2199
- Member checking, 408
- Membership categorization analysis, 275–276
- Memory work, 528
 - analysis, 533–535
 - as autoethnography, 529
 - as collective method, 529
 - ethical considerations, 536–537
 - as research approach, 530
 - rewriting memories, 535
 - social theories, 535–536
 - and social transformation, 536
 - theme/question, identification of, 531–532
 - writing memories, 532–533
- Memo writing, 1570
- Mental Capacity Act, 1996, 1998
- Mental health, 2094, 2106
- Mental models, 110–112
- Meta-analysis, 807, 811, 814, 820–822, 824
- Meta-ethnography, 792, 799, 800
- Metaphorical analysis, 1747
- Meta-summary, 792, 793
- Meta-synthesis, 807, 817, 824
- Meta-synthesis of qualitative health research, 786–788
 - assessment, 799
 - content analysis, 796
 - epistemological position, 789, 790
 - inclusion/exclusion criteria, 795–796
 - keywords/search terms, 795, 797
 - objectives, 788, 789
 - paradigm dimension, 790–793
 - protocol, 797
 - quantitative approaches, 789
 - question design, 793–795
 - reciprocal translation, 799
 - scope, 793
 - searching and selection/sampling studies, 798
 - systematic reviews, 787
 - text mining tools, 797
- Meta-theory, 792
- Methodological approach, translation, *see* Translation
- Methodological quality, 1030, 1032–1034, 1047, 1054
- Methodology, 1693–1695, 1697–1703, 2113
 - life history interview as, 427–430, 438
- Methods section, 989–992
- Migrant and ethnic minority (MEM) groups, 1740
- Migrant and refugee children, visual research, 1728–1734
 - See also* Visual research
- Mind mapping
 - assessment, 1120–1123
 - case study, 1123–1125
 - construction of, 1116
 - data analysis, 1118–1119
 - data collection, 1118
 - definition, 1115
 - health and social sciences, 1125–1126
 - and mixed methods, 1123
 - plan research, 1117–1118
 - presenting data, 1119–1120
 - theory and methods, 1116–1117
- Minds maps, 1076
- Minority recruitment, 93

- Mixed methods, 684, 696, 697, 919, 921, 922, 933
 - data analysis and integration, 707–708
 - data collection and sampling, 705–707
 - handling conflicting results from, 710–711
 - reporting of, 708–709
 - study designs, 699–704
- Mixed methods appraisal tool (MMAT), 1053–1057
- Mixed methods research (MMR), 4, 7, 52, 62, 67, 68, 752–753
 - convergent criteria, 1052
 - convergent design, 63
 - definition, 52–53
 - evolution of, 53–54
 - explanatory sequential design, 63–64
 - exploratory sequential design, 64–65
 - feasibility, 1058
 - foundational element, 1057
 - in health social sciences, 54, 56–57
 - hybrid design, 66–67
 - individual components approach, 1053
 - inference transferability, 1061–1062
 - integration, need for, 1064
 - interpretive rigor, 1060–1061
 - intervention design, 65–66
 - MMAT, 1054
 - philosophical positions (*see* Philosophical positions)
 - planning transparency, 1058
 - quantitative and qualitative components, 1063
 - rationale transparency, 1058
 - report availability, 1062
 - reporting transparency, 1062
 - research questions and methodology, 1063
 - transparency, need for, 1063
 - undertaking research phase, quality criteria for, 1058–1060
 - use of, 1064
 - yield, 1062
- MNL, *see* Multinomial logit (MNL)
- Mobile research method, *see* Walking interviews
- Mobilities, 1272
- Modified Delphi, 718, 724
- Mothering, 2094, 2095, 2100
- Mothers, drawing method, *see* Drawing method
- Motivation, 1901
- Multicultural society, 1499
- Multi-methodological research, 357
- Multinomial logit (MNL), 631
- Multiphase design, 704
- Multiple-case design, 321
- Multivariate approach, 614
- Music therapy, 1137
- N**
- Nanomedicine, 1173
- Narrating Our World (NOW) project, 1732
- Narrative analysis, 863, 866, 868
 - and analysis of narratives, 870
 - and cognition, 868–869
 - findings of, 876
 - outcomes of, 875
 - techniques, 871–872
- Narrative inquiry, 862, 863, 869–571, 874, 877, 878
 - in health and social sciences, 865–866
- Narrative research, 413
 - advantages, 419
 - autobiographies, 414
 - disadvantages, 420
 - formal structural and functional analysis, 416
 - health and social sciences research, 418–419
 - interpretation, 417–418
 - lived, 414
 - person-centered therapy, 414
 - place, 415
 - relational, 413–414
 - sociality, 415
 - temporality, 415
- Narrative synthesis, 789, 795
 - CERQual approach, 801
 - PICOS approach, 795
- Narrative therapy, 1246
- National Health and Medical Research Council (NHMRC), 287
 - hierarchy, 1029
- Naturalistic generalizations, 326–329
- The Nature of Qualitative Research, 912
- Needs analysis, 357–358
- Netiquette, 1396
- Netnography, 1083, 1322–1323
 - conducting ethical, 1329–1332
 - data analysis, 1328–1329
 - data collection, 1327–1328
 - data set size, 1334
 - defined, 1323–1324
 - ethical considerations, 1332
 - in health social science research, 1324
 - lack of face-to-face interaction, 1332
 - planning and Entrée, 1325–1327

Netnography (*cont.*)

- process, 1325
- researcher as participant, 1333–1334
- research representation and evaluation, 1329

Neutral patient model, 209

New media, 2128

The New mobilities paradigm, 1272

New public management (NPM), 216

New Zealand, 1692, 1695, 1699–1702

Nominal group technique (NGT), 738

- advantages and disadvantages, 745–747
- establishing core outcomes, 740–741
- guideline development, 739
- identifying research priorities, 739–740

Non-Indigenous Australians, 1546

Non-reversible behaviors

- AATD, 592
- demonstration designs for, 589

Normativism, 107

Normativity, 134, 135, 138, 141, 144

NVivo, 926, 932

O

Objectivist research, 300–302, 308, 314

Observation, 497–499

Observer bias, 666

Odds ratio (OR), 569

One-off consent process, 1996

Online anonymity, 1358–1360

Online Delphi, 720

Online face-work, audiences and, 1358–1360

Online research methods, 1323

Online survey methods

- advantages and problems associated with, 1341–1342
 - critiques of, 1342–1343
 - data collection and analysis issues, 1347–1348
 - enhancing response rates using, 1346–1347
 - measurement issues with, 1345
 - platforms and services, 1348–1349
 - resources for creating/managing, 1347
 - sampling issues and, 1344–1345
- Online surveys, 542, 545, 548, 552–554
- merits and limitations of, 553–554
 - potential biases, 546–547
 - sample sizes for, 548
 - social desirability, 549–550

Ontology, 101–102, 161, 164, 165, 167, 192, 199

Operant psychology, 583

Optimal matching (OM), 948

Oral history interviewing, 393

Oral History Society, 430

Oral standard variety/oral cultured norm, 1622

Outsiders, 1609–1610

P

Paired t-test, 674

Panel, 719

Paradigmatic analysis of narratives, 869, 870, 872

Paradigms, 301, 302, 314

Parallel cueing, 1227

Parallel studies, 654

Parenting, 1894, 1899

PAR, *see* Population attributable risk (PAR)

Participant engagement, 77

Participant feedback, 1807

Participant-guided mobile methods, 1081, 1292–1293

- data from diverse participants, 1298–1299
- eliciting different data, 1297
- enabling complex insights, 1299
- limitations and challenges, 1300–1301
- power and control, 1293–1295
- risks to consider with mobility, 1298
- spatially-situated research, 1295–1297

Participant observation, 448–449

Participant voice, 1930

Participation process, 1170

Participatory action research (PAR), 103, 286

- flexibility and interdisciplinarity, 1744
- migration, gender scripts and cultural change, 1748–1752
- Roma youth and drug use, 1744–1748
- with youth, 1741–1742

Participatory analysis method, 1307, 1308, 1313

Participatory justice, 1170

Participatory methods, CBPR, *see* Community based participatory research (CBPR)

Participatory research, 1266, 1576, 1712, 1717

- description, 1920–1922
- models, 1926–1930
- principles, 1930–1932
- visual methods for children and young people, 1726–1728
- vulnerability, 1922–1926
- with children and young people, 1725–1726

Participatory research methodologies, 1875–1876

- Participatory video, 1743
- Paternalism, 208–210
- Paternalistic model, 208–209
- PCP, *see* Personal Construct Psychology (PCP)
- Pedagogy, 2214, 2222
- Peer research, 1742
 - migration, gender scripts and cultural change, 1748–1752
 - Roma youth and drug use, 1744–1748
- Personal construct psychology (PCP), 1075, 1096
 - analysis of constructs, 1105
 - constructivist epistemology, 1096–1097
 - constructs and construing, 1097–1098
 - cross-cultural perceptions, 1099–1100
 - elicitation constructs in interview, 1099–1100
 - features, 1098–1099
 - interviewing using elicited constructs, 1101–1102
 - laddering, 1102–1104
 - pictor technique, 1105–1108
 - reflecting on use of, 1110
 - self-characterization sketch, 1109–1110
 - triadic method of construct elicitation, 1100–1101
- Person-centered healthcare (PCH), 215, 217
- Person-centered therapy, 414
- Perspective-taking, 239, 242–245
- Phenomenology, 1831–1832
- Philosophical positions
 - frameworks, 57–59
 - paradigmatic challenges and successes, 59–61
- Philosophical stances, 108
- Philosophy, 239
- Photo-elicitation, 450, 1455, 2032
 - methodologies, 1732
- Photographic diary method, 1925
- Photolanguage, 1878–1879
- Photovoice, 1148, 1455, 1732–1733, 1750
 - autism, 1158–1161
 - data analysis, 1151–1152
 - HIV/AIDS, 1152–1158
 - method, 1078
 - procedures, 1150–1151
 - in public health, 1149
 - theoretical basis, 1149
 - uses, 1148
- Pictor technique, 1105–1108
- Pilot testing, 639
- Pitt County Study, 1232–1233
- Placing issues in cross-cultural and sensitive research
 - age issues, 1607–1608
 - gender issues, 1604–1607
 - race, culture and ethnicity issues, 1608–1610
 - shared experiences, 1612–1613
 - social class issues, 1610–1612
- PlayDecide card game, 1171
- PMS, *see* Premenstrual syndrome (PMS)
- Poetry, 2066, 2071–2072, 2075, 2076
- Police research, 2181–2185, 2190
 - access negotiation, 2189–2190
 - cultural barriers, 2183
 - knowledge exchange and dissemination, 2191–2192
 - lack of trust and cross-cultural communication, 2184–2185
 - research by the police, 2185, 2186
 - research for the police, 2185, 2186
 - research on the police, 2185, 2186
 - research with the police, 2185, 2186
 - trust, establishment of, 2190–2191
- Political epistemology, 135
 - critical theory, 135
- Politics of representation, 2085–2087
- Polyglossia, 1622
- Popper, Karl, 159
- Population attributable risk (PAR), 570
- Positionality, 1603
- Positivism, 153, 154, 834
 - health social sciences research, 160
 - logical, 157
 - post-positivism, 158–160
 - social sciences and Comteian classical positivism, 156–157
 - western science and positivist notions, emergence of, 155–156
- Postal Delphi, 719
- Postnatal depression (PND), 2094, 2095, 2098, 2099, 2107
- Postpositivism, 58, 60
- Power relations, 126
- Practical, robust implementation and sustainability model (PRISM), 380
- Practice-based research, 525
- Pragmatic-explanatory continuum indicator summary (PRECIS) tool, 376
- Pragmatic trials, 376–377, 658–659
- Pragmatism, 59, 61, 1097
- Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation-Policy, Regulatory, and

- Organizational Constructs in Educational and Environmental Development (PRECEDE-PROCEED) model, 342
- Preference elicitation, 625–627
- Preferences and values, 626
- Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, 972, 1052
- Premenstrual dysphoric disorder (PMDD), 885
- Premenstrual syndrome (PMS), 889
 - biomedical constructions of, 891
 - facilitating agency and self-care, 892–893
 - feminist Foucauldian discourse analysis of, 889
- Prevalence, 566–567
- PRISMA guidelines, 798
- Prison
 - corrections, 2167
 - nature of, 2166–2167
- Privacy, 1892, 1897–1898
- Process evaluation, 359–362
- Program design, 517, 520
- Program evaluation, 342
- Prostitution, 2116, 2118
- Protocol design, 653
- Protocol registration, 653–654
- Psychiatric art, 1136
- Psychological dimension, 2012–2013
- Psychology, 239
- Public health, 1148, 1149, 1161
 - evaluation research (*see* Evaluation research)
 - and police research (*see* Police research)
 - research, 224, 234
- Public policies
 - definition, 1002
 - and research findings (*see* Research findings and public policies)
- Purposive sampling, 18
- Q**
- Q Assessor, 757, 758
- Q methodology
 - advantage, 762
 - bi-person factor analysis, 757
 - concourse development, 754–755
 - definition, 753
 - factor analysis, 753–754
 - factor array, 758–761
 - limitations, 758, 762–763
 - pros and cons of, 763, 764
 - P set selection, 755
 - Q Assessor analysis, 758
 - Q set, 755
 - Q sorting, 756–757
 - subjectivity, 762
 - traditional statistical software, 758
 - user participation, 762
- Q sorting
 - electronic techniques, 757
 - manual techniques, 756
 - Q Assessor, 757
- Qualitative analysis, 1163
- Qualitative data
 - analysis, 20–21
 - collection methods, 17–18
 - schema analysis (*see* Schema analysis)
- Qualitative data analysis software (QDAS), 919
 - case's code, 923
 - comparative analyses, 931
 - folders, 923
 - goals of analysis, 919–921
 - matrix coding query, 932
 - reviewing and exploring data, 924–926
 - selecting data for analysis, 921–922
 - sets of codes, 924
 - sorting and coding data, 926–931
 - users of, 919
- Qualitative description, 836
- Qualitative inquiry
 - analytic strategies, 20–21
 - description, 10
 - features, 11
 - vs. qualitative research, 12–14
 - real-world issue examination, 12
- Qualitative interviewing, 2045
 - advantages, 393–394
 - aims, 393
 - case studies, 394–399
 - description, 393
 - participant selection, 400–401
 - planning, 402–403
 - practice, 404–408
 - recruitment, access and ethics, 402
- Qualitative, meaning/terminology, 10
- Qualitative methodology, 1958, 1959
- Qualitative methods, 2199
- Qualitative/quantitative research, 109–110
- Qualitative research, 4, 5, 300, 301, 476, 482, 1014–1016, 1018, 1020, 1022–1025, 1114, 1184, 1187, 1193, 1239, 1244, 1251, 2146, 2154, 2216
 - appraising, 1015–1016
 - approach, 11

- challenges of, 974
- conceptualizing rigor in, 1016–1017
- dementia, 1996
- guidelines for appraising, 975–977, 1021–1024
- inductive approach, 15
- mapping stages of, 1118
- method, 318, 320, 1877–1879
- methodological frameworks, 16–17
- and mind mapping, 1115–1116
(*see also* Mind mapping)
- proposed strategy for, 1024–1025
- research assistants (*see* Research assistants)
- saturation, 19
- source of data, 18–19 (*see also* Qualitative inquiry)
- standards of, 973
- and trustworthiness, 19–20
- with children, 2026
- Qualitative researchers, 14, 15
- Qualitative research, multiple language groups
 - budget, 1671
 - confidentiality, 1669
 - constructivist grounded theory, 1655, 1656
 - co-participants, 1663
 - cultural competency training, 1658
 - data analysis, 1669–1670
 - debriefs, 1667
 - informed consent, 1662–1663
 - interpretation method, 1666
 - interpreters and translators, 1657–1658
 - interview data, transcription of, 1670
 - interview guide, 1664–1665
 - language use, 1667–1668
 - pre-brief meeting, 1665, 1666
 - reporting findings, 1670–1671
 - second interviews, 1668–1669
- Qualitative story completion method, 1086
- Quality, 973, 974, 982
 - criteria, 1015, 1021, 1023, 1025
- Quality of life (QOL), 546
- Quantitative analysis, key measures/ variables for, 991
- Quantitative data analysis, 956
 - bivariate analysis, 962
 - causal research questions, 960
 - choice of analysis model, 965
 - descriptive analysis, 962
 - descriptive statistics, 963
 - exploratory research questions, 960
 - inferential analysis, 963, 965
 - levels of measurement (*see* Levels of measurement)
 - multivariate analysis, 962
 - practice of, 965–968
 - relational research questions, 960
 - statistical hypothesis, 964
 - univariate analysis, 961, 962
- Quantitative, meaning/terminology, 10
- Quantitative research, 4, 6, 7, 29, 1028, 1047
 - benefits, 30
 - bias, 41
 - defined, 29
 - development, 36–37
 - evidence pyramid, 38
 - experimental, 30
 - interpreting, 29, 47–48
 - limitations, 30
 - methods, 1876–1877
- Quasi-experimental study, 564
- Questionnaires
 - data quality, 546
 - focus group, 555
 - format and design, 544–545
 - potential biases, 546–547
 - validity and reliability, 545–546
- R**
- Racism, 257
- Radical objectivity, 218
- Random digit dialing (RDD), 1405
- Random error, 571–572
- Randomization, 648–649
- Randomized controlled trials (RCT), 160, 375, 384, 564, 647–648
 - allocation concealment, 649
 - blinding, 649–650
 - cluster, 655–656
 - comparative effectiveness research, 659
 - crossover, 656–657
 - factorial design, 654–655
 - IIT analysis, 650–651
 - parallel, 654
 - pilot studies, 652
 - pragmatic, 658–659
 - protocol design, 653
 - protocol registration, 653–654
 - randomization, 648–649
 - reporting of, 657–658
 - superiority, equivalence and non-inferiority, 657
- Random utility theory (RUT), 629
- Ranking, 743, 745
- Rapid ethnography, 1292

- Rapport, 405
- Rating scale scores, 111
- RCT, *see* Randomized controlled trials (RCT)
- Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) model, 379–380
- Realism, 161
- critical, 164–165
 - scientific, 161–162
- Realistic evaluation theory, 340
- Realist research, 300–302, 309, 310
- Recruiting Older Adults into Research (ROAR) Toolkit, 90
- Recruiting participants
- drug use, 1975
 - fentanyl use, 1977
 - health care, 1975
 - reduce gatekeeping, 1976
 - snowball sampling, 1977
- Recruitment strategies, 77–79
- adults, 81–90
 - barriers and challenges, 74–75
 - children and young people, 79–81
 - facilitators, 75–77
 - older adults, 90–92
- Reflexive practice, 260
- Reflexive thematic analysis, 848–849
- candidate themes, 854
 - constructing themes, 854
 - design considerations, 849–852
 - familiarization, 852–853
 - generating codes, 853–854
 - producing the report, 857
 - revising and defining themes, 855
- Reflexivity, 274, 446–447, 536, 1643
- emotional management, 2175
 - managing boundaries, 2174–2175
- Refugee(s), 1812, 1816, 1818, 1821, 1824, 1826, 1873–1875, 1884–1885
- camp, 1813, 1816, 1820, 1824
 - women, drawing method and infant feeding practices (*see* Drawing method)
- Refugee children
- CAIs (*see* Computer-assisted interviews (CAIs))
 - respect, 1780
 - well-being, 1781
- Register, 1621
- Relational aesthetics, 1135
- Relational map, 1263–1265
- Relational narrative, 413–414
- Relativism, 1097
- Reliability
- data collection, 667
 - external factors, 667
 - internal consistency, 668–669
 - inter-rater/inter-observer, 668
 - researcher/observer, 666
 - respondent, 667
 - sources of errors, 666–673
 - test-retest, 668
- Repeated measures
- ANOVA, 612–614
 - classic repeated measures and growth curve designs, 606–607
 - correlation structure, 615–616
 - crossover designs, 607–609
 - marginal models, 618–619
 - mean plots, 610–612
 - missing data, 614–615
 - mixed model regression approach, 615
 - multivariate approach, 614
 - panel plots, 609–610
 - transition models, 619
- Report availability, 1062
- Reporting
- bias, 994
 - checklists, 987–995
 - quantitative findings, 989
 - of study design, 990
 - sufficient and relevant information, 990
 - transparency, 1062
- Reporting guidelines, 972–974, 979, 982, 987–995
- for qualitative research, 974–977
- Reporting quality, 1062
- definition, 1034
 - of experimental studies, 1040
 - of studies, 1046
 - systematic reviews, 1034–1035
- Representativeness, 548–549, 556
- Research, 3, 4, 6, 152–154, 160, 165, 1240, 1245–1247
- aims, 2183, 2193
 - approach, 4, 5
 - design, 54, 56, 60
 - ethics, 1854, 1856, 1858, 1859, 1863, 1974–1975
 - people with dementia (*see* Dementia)
 - with young people, 1725–1726
 - See also* Body mapping
- Research assistants
- in academic and non-academic institutions, 1677
 - conceptual and ethical issues, 1686–1688

- definition, 1677
 - interpreters, 1677
 - large-scale surveys, implementation of, 1677
 - recruitment of, 1680–1684
 - researcher, position of, 1678
 - research timeframe and funding, 1679
 - role of, 1679
 - tasks, 1684–1686
 - Researcher status, 2189
 - Research findings and public policies
 - academic research, 1008
 - action research, 1008
 - communicational obstacles, 1005
 - credibility and communication, 1005
 - decision-making process, 1006
 - enlightenment model, 1004
 - epistemic-praxis obstacles, 1005
 - historical-political obstacles, 1005
 - influence and legitimacy, 1005
 - instrumentation research, 1008
 - interactive model, 1004
 - knowledge driven-model, 1003
 - knowledge transfer, 1005
 - philosophical obstacles, 1005
 - planning research, 1008
 - political model, 1004
 - politics and institutions, 1005
 - problem solving model, 1004
 - research quality, 1007
 - social researchers, 1007
 - tactical model, 1004
 - tactic obstacles, 1005
 - temporary obstacles, 1005
 - Research methodology
 - methods section, 989–992
 - novelty in, 987
 - Research methods
 - innovation and use of technologies, 688–689 (*see also* Integration)
 - mixed methods, 683–684
 - mixed research, 2016
 - qualitative, 2015
 - quantitative, 2013–2014
 - recommendations for projects, 690
 - researcher role, 687–688
 - triangulation, 683
 - Research with prisoners
 - prisoners lives, 2167
 - prisons nature, 2166–2167
 - reflexivity, 2173–2175
 - sensitive contexts for, 2168–2170
 - Resilience, 257–258, 2045, 2047, 2054, 2056, 2057
 - Respect, 1780, 1783, 1787, 1788, 1790, 1791
 - Response rates, 1418, 1419, 1425
 - online survey, 1346–1347
 - Results based management (RBM), 341, 342
 - Results section, 992–993
 - Retrospective data, 940
 - Reversible behaviors
 - ATD, 591
 - demonstration designs for, 588
 - Rigor, 839, 1014–1017, 1021, 1022, 1945
 - Risk of bias, 807, 812, 816, 818–820, 822, 824
 - Risk ratio (RR), 568
 - Roma youth
 - peer research on migration, gender scripts and cultural change, 1748–1752
 - visual and participatory research, 1744–1748
 - Rorschach inkblot test, 1481
 - Running records, 495
 - RUT, *see* Random utility theory (RUT)
- S**
- Salutogenic approach, 2012, 2013
 - Scheme analysis, 898, 900–901
 - group/meta-schemas, 903–904, 908–911
 - individual schemas, 901–903, 905–907
 - interpretation of meta-schemas, 904, 911–912
 - qualitative analytic practices, 912–913
 - validity, rigor and trustworthiness of data, 912
 - Science and Technology Studies (STS), 2199
 - Scientific antirealism, 162–163
 - Scientific realism, 161–162
 - Script writing, 1306
 - Search strategy, 809, 810, 812, 813
 - Selection bias, 573
 - Self-administered freelists, 1435
 - Self-characterization sketch, 1109–1110
 - Self-initiated experiential education project (SEEP), 327
 - Self-portrait(s), 1258–1262
 - method, 1080
 - Self-report methods, 496
 - Semantic, 853
 - Semi-structured interviews, 393, 402
 - Semi-structured life history calendar (SSLHC) method, 1202, 1207, 1210, 1215

- Sensitive research, 2112–2113, 2124, 2168
 age issues, 1607–1608
 and emotions (*see* Emotions and sensitive research)
 gender issues, 1604–1607
 race, culture and ethnicity issues, 1608–1610
 shared experiences, 1612–1613
 social class issues, 1610–1612
- Sensitive research methodology and approach
 animated visual arts and mental welfare fields, 1913
 dementia, people with, 1911
 disability research, 1911
 eating disorders and child sexual abuse, 1912
 elites/experts, 1909
 and emotions, 1914
 ethics and practice of research, 1911
 face-to-face research in prisons, 1914
 hard-to-reach people, 1910, 1914
 Internet in sex research, 1914
 marginalized people, 1908–1910
 participant-generated visual timelines, 1912
 police research and public health, 1914
 underage sex work, 1913
 vulnerable people, 1908–1910
 with children, 1912
 women's violence, 1913
- Sensitive topics, 1371, 1380, 1909, 1911, 1913, 1914
- Sensitivity
 responsiveness, 673
 sources of risk, 674
 statistical methods, 674–675
- Sensory methods, 451–452
- Sentence starters, 2034–2035
- Sequence analysis, 936–939
- Sequence data, 939–941
- Sequence probes, 406
- Sequential cueing, 1227
- Sequential explanatory design, 699–700
- Sequential exploratory design, 700–701
- Sequential multiple assignment randomized trial (SMART), 609
- Sexology, 2128
- Sexual exploitation, 2116–2118, 2121–2122
 agency and consent, 2115
 confidentiality, 2119
 gatekeepers, 2115–2116
 isolation and responding to danger, 2119–2120
 personal, social and political, 2119
 trust-building and researcher vulnerability, 2120–2121
- Sexuality, 1956–1957, 2128, 2131, 2133, 2135, 2136, 2138
 and disability, 1956–1957
 IHPA (*see* Interpretive hermeneutic phenomenological approach (IHPA))
- Shannon's entropy index, 947
- Sharing authority, 426
- Sick and disabled women, 212–213
- Simple randomization, 648
- Single-case designs, 321, 322, 326, 582
 AATD, 592
 ABAB design, 588
 ATD, 591
 baseline logic, 585–586
 development of, 583
 graphical presentation of raw data, 593
 individual case, 583–584
 multiple baseline design, 589–590
 procedural fidelity, 598
 repeated measurement, dependent variable (s), 584–585
 repeated, systematic manipulations, independent variable(s), 585
 research questions, 587–588
 response-guided decision-making vs. randomization, 598–600
 selection of dependent measures, 597–598
 visual analysis guidelines, 593–597
- Single-subject designs, *see* Single-case designs
- Situational mapping, 306, 307, 313
- Snowball sampling, 85
- Social and emotional well-being, 1708, 1710, 1717, 1719
- Social constructionism, 118, 863
 discursive psychology, 129–130
 essentialism, 122–123
 Foucauldian/critical discourse analysis, 128–129
 historical and cultural specificity, 121
 illness, 126–127
 knowledge, social processes and social action, 121–122
 language, 124
 objectivity and universalism, 124–125
 origins and influences, 118–120
 power and politics, 125–126
- Social constructivism, 163
- Social desirability, 542, 548–550, 555, 556
- Social determinants of health (SDoH), 1873, 1876, 1886
- Social exclusion, 1931, 1932

- Social justice, 286–288, 291, 295, 296
- Social mechanisms, 463
- Social media, 359, 362, 1387
- Social network analysis (SNA), 771–772
 - and health care research, 776–780
- Social network, concepts, 771–772
- Social networking sites (SNSs), 1326, 1327, 1332
- Social participation, 1565, 1576, 1577
- Social pathways, 1203, 1204
- Social position, of interpreters, 1641, 1643–1646
- Social science(s), 153, 154, 1238
 - and Comteian classical positivism, 156–157
 - critical realism in, 165
 - Dewey's approach to, 158
 - post-positivism in, 160
 - research assistants (*see* Research assistants)
- Social transformation, 529, 536
- Social vulnerability, 1908
- Social work practitioners, 1102–1104
- Sociological linguistics, 2063
- Socio-political dimension, 2009–2010
- Software, qualitative data analysis,
 - see* Qualitative data analysis software (QDAS)
- Solicited diary methods, 1085, 1448–1449
 - addressing the limitations of, 1459–1460
 - approaches to, 1451–1454
 - capture technologies, 1454–1455
 - data analyzing, 1456–1457
 - examples, 1460–1461
 - methodological underpinnings, 1449–1451
 - qualitative, 1448
 - quantitative, 1448
 - strengths and limitations of, 1457–1458
 - typology of research questions, 1452–1454
- Space and time consideration, 1628
- Specificity, 576
- SPSS, *see* Statistical Package for Social Sciences (SPSS)
- SRM, *see* Standardized response mean (SRM)
- Stability, 727, 729, 732
- Stakeholder capture effect, 1170
- Standardized response mean (SRM), 675
- Standards for Reporting Diagnostic Accuracy Studies (STARD), 973
- Standpoint theory, 462–463
 - institutional ethnographers, 458
- Statistical Package for Social Sciences (SPSS), 956, 958, 965, 966
 - statistical software, 758
- Statistics, Indigenous peoples, *see* Indigenous statistics
- Steering probes, 406
- Story analyst, 869
- Story completion (SC), 1480
 - advantages, 1483
 - analysis approaches to avoid, 1493
 - benefits of, 1482–1484
 - completion instructions for, 1487
 - data analyzing, 1491–1493
 - as data collection method, 1482–1484
 - flexibility of, 1484
 - frequency counts, 1493
 - story maps, 1491–1492
 - theoretical lens, 1481–1482
- Story completion (SC) research
 - asking additional questions in, 1488
 - data collection and ethical considerations in, 1489–1490
 - ethics in, 1490
 - examples, 1484
 - piloting in, 1490
 - sampling in, 1488–1489
 - stem and study design, 1484–1486
 - topics and questions, 1484
- Story map, 1491–1492
 - template, 1186
- Storytellers, 413, 869
- Stratified randomization, 648
- Street-involved youth, 2044, 2045, 2047, 2057
- Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement, 972, 987
- Strengths-based research, 1716, 1719
- Strengths, weaknesses, opportunities, and threats (SWOT) analysis, 358
- Structured vignette analysis, 1831, 1836–1839
- STS, *see* Science and Technology Studies (STS)
- Study participants, 78, 91
- Subjective idealism, 789
- Subjectivity, of interpreters, 1641, 1643–1646
- Substance treatment
 - cognitive impairment, 1984
 - drug treatment, 1983
 - treatment program, 1984
- Suicide research, Aboriginal people,
 - see* Aboriginal people
- Summative content analysis, 829–830
- Summative evaluation, 361–362
- SurveyMonkey®, 1390

- Surveys, 175–176
 definition, 542
 traditional (*see* Traditional surveys)
- Survival analysis, 619
- Sustainable developmental goal (SDG), 555
- Symbolic interactionism, 170
 content analysis, 178–179
 ethnographies, 176–177
 experimental methods, 179–180
 interview methods, 173–174
 methodological divergence, 172–173
 surveys, 175–176
 tenets and propositions of, 170–171
- Synchronous text-based online interviewing
 method, 1084, 1370, 1373, 1378–1381
 development, 1371–1373
 interviewer effect, 1371–1372
 potential interviewees, 1372
 preference method, 1375–1378
 usage, 1373–1375
- Systematic analysis, 480
- Systematic error, 571, 573
- Systematic reviews, 807, 809, 811
 protocols, 811–812
 stages of, 808
- T**
- Target population, 73, 77, 81
- Team-working, 899, 903
- Technology, 2128, 2133, 2135, 2138
- Teddy diaries, 1086, 1466–1467
 bear qualities, 1472–1474
 collective voice development, 1469–1470
 comparative analytical context, 1468–1474
 home–school communication, 1468–1474
 interpretations of, 1468
 significant routines, 1470–1471
 socially saturated naturally occurring data, 1467–1468
- Telephone interviewing practice
 recommendations, 1425–1428
- Telephone surveys, 1420
 interviewers, 1418–1420
 nonresponse to, 1418
- Temporality, 575
- Test-retest reliability, 668
- Textual analysis, 464, 1788
- Textual method of inquiry, 1085
- Thematic analysis (TA), 901
 codebook, 849
 coding reliability, 847–848
 domain summaries vs. shared-meaning-based-patterns, 845–847
 history, 844–845
 method, 20
 reflexive (*see* Reflexive thematic analysis)
- Thematic map, 855, 856
- Theme, 845–849
 candidate, 854–855
 constructing, 854
 revising and defining, 855–857
- Theoretical appropriateness, 1779, 1790
- Theoretical questions, 1618
- Theoretical sensitivity, 688
- Theory based evaluation, 335–336
 realistic evaluation theory, 340
 ToC, 336–340
- Theory of change (ToC), 336, 337
 CCM, in Indonesia, 339
 and classic change theories, 339–340
 elements, 338
 mapping, 338
- Thick description, 1788
- Time diary methods
 conversational survey technique, 1226
 cueing properties, 1227
 National Time Accounting framework, 1229–1230
 well-being and surveys, 1224–1227
- Timeline(s), 1184, 1185, 1191, 1192, 1197
 concept inclusion, 2045
 critical emancipatory and feminist approach, 2056
 data analysis, 2046–2047
 diagramming methods, 2054
 drawing method, 1079
 implementation, 2055
 mapping to participants, 2047–2048
 organize and accumulate data, 2055
 participant as navigators, 2052–2053
 rapport building, 2050–2052
 sequencing of events, 2056
 styles, 2048–2049
 therapeutic moments and positive closure, 2053–2054
 visual, 2046
See also Timeline drawings
- Timeline drawings
 advantages, 1187–1189
 challenges, 1189–1191
 definition, 1185
 four-phase model, 1197–1198
 review, 1191–1197

- Time use research, 1221
 - description, 1222
 - well-being, 1223–1224
 - Top-down cuing, 1227
 - Total institution, 2166
 - Traces, 492–494
 - Traditional surveys
 - data quality, 546
 - ethics, 554–555
 - F2F surveys, 555
 - and ICT based surveys, 551–553
 - interviewer bias, 550–551
 - merits and limitations of, 553–554
 - pilot test, 555
 - potential biases, 546
 - primacy and recency effects, 551
 - questionnaire format and design, 544–545
 - reliability and validity, 545–546
 - representativeness, 548–549
 - social desirability and acquiescence bias, 549–550
 - sustainable developmental goal, 555
 - Training, 2152, 2156
 - Transferability, 1964
 - Transformative design, 703–704
 - Translation, 1622–1623, 1640, 1642, 1646–1647, 1657, 1659, 1662, 1666
 - competence, 1629–1630
 - cultural issues, 1623
 - difficulties, strategies and rules, 1626–1629
 - ethical issues, 1620–1621, 1630–1632
 - grammatical issues, 1623
 - lexical issues, 1619
 - linguistic treatment, 1623–1624
 - pragmatic issues, 1623
 - rhetorical issues, 1623
 - semantic issues, 1620
 - syntactic issues, 1620, 1623
 - task of, 1624–1626
 - Translational research
 - business research methods, 381–382
 - collaboration and community engagement, 385
 - decision analysis, 380
 - definition, 369
 - external validity, 383–384
 - fidelity research, 382–383
 - health social science research, 372–373
 - hexagon tool, 378–379
 - humans, 375
 - hybrid research models, 375–376
 - non-reflexive and reflexive clinical research, 372
 - pragmatic trials, 376–377
 - PRISM, 380
 - RE-AIM model, 379–380
 - theoretical research, 374
 - types, 369–370
 - Trauma aware practice, 256
 - Triadic method, 1100–1101
 - Triangulation, 683
 - Trustworthiness, 19–20, 1016, 1963–1968
 - Turbulence, 947
 - Twenty statements test (TST), 175
- U**
- Unmotivated looking, 480
 - Unobtrusive methods
 - episodic records, 496–497
 - and ethics, 499–500
 - generative problem, 502–503
 - online methods, 500–501
 - running records, 495
 - traces, 492–494
 - triangulation, 502
 - User led research, 1937
- V**
- Validity
 - action inference, 672
 - cellphone surveys, 1408
 - construct, 670–671
 - content, 670
 - criterion, 671–672
 - interpretive inference, 672
 - Verstehen, 196–197
 - Victims, 2112, 2114, 2119, 2121, 2122
 - Vignettes, 1831, 1832, 1834, 1836, 1837, 1841–1842, 2033–2034
 - Violence, 2112, 2113, 2115, 2120, 2122, 2123
 - Visual analysis, 1814, 1818, 1823, 1826, 1827
 - Visualization, graphical
 - index plot, 942–944
 - modal plot, 945
 - state distribution plot/chronogram, 944–945
 - Visualizing, 919
 - Visual maps, 1125
 - Visual methodology, 1240, 1251
 - Visual methods, 449–451, 2055, 2056
 - maps, 1262–1265
 - self-portraits, 1258–1262
 - Visual narrative inquiry, 1195
 - Visual representations, 1813, 1817, 1822, 1826

- Visual research, 1077, 1724
 calendar and time diary methods, 1079, 1080
 card-based discussion method, 1078, 1079
 maps and drawings, 1728–1732
 methods, 1148
 participatory methods, 1726–1728
 photographs and videos, 1732–1734
 photovoice method, 1078
 semi-structured life history calendar method, 1079
 timeline drawing method, 1079
 with marginalized youth, 1742–1744
- Voice
 negotiating, 1310
 producing, 1309
- Volunteer Family Connect (VFC) program, 373, 387
- Vulnerability, 2113, 2118, 2120–2123
- Vulnerable groups, 1923
- Vulnerable people, 1908, 1911, 1913
- W**
- Walking interviews, 1081, 1292, 1296
 case studies, 1283–1287
 conducting, 1281–1283
 considerations and limitations, 1279–1281
 description, 1270, 1271
 ethical considerations, 1282
 strengths and characteristics, 1272–1279
- War metaphors, 212
- Web-based survey
 data collection and analysis issues, 1347–1348
 platforms and services, 1348–1349
- Web-based survey methodology, 1083
- Well-being, 106, 108, 114
 calendar interviewing methodology, 1231–1233 (*see also* Calendar methods)
 flexible conversation techniques, 1225
- National Time Accounting framework, 1229–1230 (*see also* Time diary methods)
- White guilt, 262
- Womanism, 1582
- Women, 2062
 Bakhtin's authoritative and internally persuasive discourse, 2065
 Bakhtin's dialogism, feminist approach to, 2063–2065
 child sexual abuse and eating disorders, experiences of, 2067–2068
 dialogical semistructured interviews, 2068–2071
 oppression of, 2066
 poetry, 2071–2072
 visual methods, 2072–2075
- Women's violence
 allegiance, 2083–2085
 ambivalence and compromise, 2087–2089
 feminist methodologies, 2080–2083
 politics of representation, 2085–2087
- Writing strategies
 author's original research on, 995
 BI section, 989
 journal articles, 987
 quantitative research, 996
 results section, 992–993
 scientific paper, 996
- Written standard variety/written normative language, 1622
- Y**
- Yarning, 1575
- Youth, 2027, 2035
 interview methods for disabled (*see* Interview methods, disabled children)
 mental health research, 1307